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# Couples' experiences after a traumatic brain injury: A mixed-method synthesis and qualitative study

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August 2018

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## **Abstract of Thesis**

**Background:** Traumatic brain injuries (TBIs) can result in a number of consequences for those who have sustained the injuries, as well as having an impact on their wider system. Estimates of divorce and relationship dissolution among couples following TBI can be as high as 54% and partners are reported to experience high levels of stress. The majority of studies have explored couples' relationships following TBI from the perspective of either the person with TBI or the partner, as opposed to exploring this dyadically and, therefore, limiting the holistic understanding to this topic.

**Aim:** The two aims of this thesis are as follows: firstly, the mixed-method synthesis review aimed to explore the current dyad evidence-base around couples' experiences and relationships following TBI; and secondly, the qualitative study aimed to explore the impact of TBI on couples' experiences and relationships.

**Method:** The systematic review's search strategy consisted of a computerised search across five databases and manual searches for further references in other relevant literature reviews and reference lists. The quality of the qualitative and quantitative studies were analysed separately. Metaethnography was employed to synthesize the findings from the qualitative studies. In the qualitative empirical study, five dyad-couples participated in the semi-structured interviews. The individuals with TBI and their partners were interviewed independently. The data collected was analysed using a combined deductive-inductive framework analysis approach, which supported comparisons between and within couples.

**Results:** The systematic review yielded eight eligible studies, three quantitative and five qualitative studies. Review of the quantitative studies suggested couples reported poor relationship quality and partners reported more dyadic dissatisfaction and overall poorer relationship adjustment than the people with TBI. Analysis of the qualitative studies suggested there were significant variations in the way couples' experience and respond to TBI. This included individual responses from the people with TBI, their partners or collectively as a couple, which influenced their relationship dynamics and also how they coped. The findings also drew attention to other contextual factors that influenced couples' attributions and perceptions toward the TBI-related changes.

Deductive and inductive analysis of the interviews in the qualitative empirical study identified three overarching themes: '*You begin to realise that, actually, life may not be the same ever [again]...*'; perceived influences on relationship endurance following TBI; and contextual and other factors. These explored the impact of TBI on couples' relationships and the processes that interacted with or influenced their perceived relationship endurance.

**Conclusion:** Although limited by a small number of eligible studies in the systematic review and small sample size in the qualitative empirical study, this thesis emphasized the importance of dyadic research for gaining a holistic understanding of couples' experiences and relationships following TBI. This allows the complex interplay between the TBI, the person who has suffered the TBI, their partner and their relationship to be better understood. The interconnectedness between the individuals and how the difficulties are experienced raises possible issues for healthcare services around their views and approaches to the individual with TBI, their partner and the couple's relationship during the recovery and rehabilitation journey.

## **Lay Summary of Thesis**

**Background:** Head injuries or traumatic brain injuries (TBIs) can result in a number of consequences for those who have sustained the brain injuries, as well as having an impact on the people around them. Up to half of couples' relationships following TBI can result in divorce or relationship breakdown and it has also been reported that partners often experience high levels of stress. The majority of studies around couples' relationships following TBI have only explored this from the perspective of one person in the couple, rather than including both the person with TBI and their partner.

**Aim:** The two aims of this thesis are as follows: firstly, to systematically review the current available research looking at couples' experiences and relationships following TBI where both the person with TBI and their partners had been involved; and secondly, the qualitative empirical study aimed to explore the impact of TBI on couples' experiences and relationships.

**Method:** Five research databases and relevant reference lists were systematically reviewed for eligible studies relating to couples' experiences and relationships following TBI. Both qualitative and quantitative studies were included in the final findings synthesis. In the qualitative empirical study, five couples agreed to participate in the semi-structured interviews. The individuals with TBI and their partners were interviewed independently. All interviews were transcribed, and the interview transcripts were analysed using framework analysis.

**Results:** The systematic search of the databases and relevant reference lists identified eight eligible studies, three quantitative and five qualitative studies. Review of the quantitative studies suggested couples reported poor relationship quality and partners reported more dissatisfaction and overall poorer relationship adjustment than the people with TBI. Analysis of the qualitative studies suggested that how couples experienced and responded to TBI varied. There was variation between the individual responses from the people with TBI, their partners or collectively as a couple, which influenced their relationship dynamics and also how they coped. The findings also drew attention to other contextual factors that seemed to influence how couples made sense of the TBI-related changes.

When exploring the qualitative empirical study's interview transcripts for patterns and themes, three overarching themes were identified: '*You begin to realise that, actually, life may not be the same ever [again]...*'; perceived influences on relationship endurance following TBI; and contextual and other factors. These explored the impact of TBI on couples' relationships and the possible factors and processes within the couples' relationship that influenced their perceived relationship endurance.

**Conclusion:** Although limited by a small number of eligible studies in the systematic review and small sample size in the qualitative empirical study, this thesis emphasized the importance of including the perspectives of both the people with TBI and their partners, in order to gain a more comprehensive understanding of couples' experiences and relationships following TBI. This highlighted the unique experiences of the separate individuals follow TBI and how the individuals' experiences interacted with one another, which raises possible issues for healthcare services around how they view and approach the individual with TBI, their partner and the couple's relationship during the recovery and rehabilitation journey.

## **Glossary of key terms**

*Dyad* – refers to pair of individuals.

*Dyadic relationship* – refers to the way a pair of individuals interact and relate with one another.

*Relationship* - refers to the couples' intimate and interpersonal relationship.

*Relationship quality* - *quality* is an umbrella term that encompasses couples' evaluations of different aspects relating to their intimate interpersonal relationships (Fincham & Bradburg, 1987; Godwin *et al.*, 2011).

*Traumatic brain injury (TBI)* - refers to an injury to the brain caused by a trauma to the head (head injury).

**Chapter 1:**  
**SYSTEMATIC REVIEW**

**Couples' relationship experiences following a traumatic brain injury: a mixed-method synthesis review**

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## **Abstract**

**INTRODUCTION:** The majority of studies that have explored couples' relationships following TBI from the perspective of either the person with TBI or the partner, as opposed to exploring this dyadically. The disparity between single perspective and dyad studies have been reflected in previous narrative reviews. To date, no dyad-focused systematic review has been conducted.

**AIM:** To explore the current evidence-base around couples' experiences and relationships following TBI from a dyadic perspective.

**METHOD:** The review protocol was registered on Prospero (CRD42018087937). A systematic computerised search was conducted in Embase, MEDLINE, PsycINFO, CINAHL and ProQuest dissertations databases, using search terms associated with "traumatic brain injury" and couples or partners. Eligible studies included: studies involving dyads where one partner of the dyad had sustained a TBI, qualitative and quantitative studies and unpublished or peer-reviewed studies. The quality of the qualitative and quantitative studies were analysed separately. A metaethnography approach was employed to synthesize the qualitative studies.

**RESULTS:** The systematic search yielded eight eligible studies, three quantitative and five qualitative studies. Review of the quantitative studies suggested couples reported poorer relationship quality and partners reported more dyadic dissatisfaction and overall poorer relationship adjustment than the people with TBI. Analysis of the qualitative studies found that the person with TBI, their partner and collectively as a couple experienced and responded to TBI in a variety of ways, which had an influence on their relationship dynamics and also how they coped. The findings also drew attention to other contextual factors that influenced the couples' attributions and perceptions toward the TBI-related changes.

**CONCLUSION:** The mixed-method synthesis review highlighted the importance of adopting dyad approaches to research and, possibly, clinical practice.

**Keywords:** Traumatic brain injury (TBI), couples, relationship quality, mixed-method review, metaethnography



## 1. Introduction

It has been estimated that 91-450 per 100,000 people are admitted to hospital with a form of head injury in England each year (Tennant, 2005). Survival from a TBI can often leave an individual suffering from a range of ongoing and persistent difficulties, including physical (e.g. problems with mobility), cognitive (e.g. problems with memory, attention, executive functioning), emotional (e.g. mood swings, emotional lability) and behavioural difficulties (e.g. disinhibition, aggression) (McMillan & Wood, 2013). These can result in changes in personality, as well as changes in functional ability (e.g. employment or occupational activities) (McMillan & Wood, 2013). Considering the range of difficulties following TBI, it is unsurprising that these can lead to wider and, sometimes, profound consequences for the family and greater social system. Family members often provide a significant proportion of the individual's post-injury support and care, with estimates of 80% of family members taking on a supportive or caring role (Kraus *et al.*, 1984). Family adjustment and coping also influence the way family members are able to interact, respond and provide support to their family member with the TBI (Rotondi, Sinkule, Blazer, Harris & Moldovan, 2007), which can influence the person's overall recovery (e.g. Mauss-Clum & Ryan, 1981).

Recent studies and reviews have started to recognise the importance of differentiating between the experiences of the different family members (see Perlesz, Kinsella & Crowe, 1999; Verhaeghe, Defloor & Grypdonck, 2005) and have suggested that where family members' experiences have been combined, the individual family experiences may have been overlooked and their unique and distinct needs may have been masked. For example, one main area of comparisons within the literature has been made between partners and parents. Although research has not produced a clear picture to differentiate between carer burden, stress and distress for partners and parents (e.g. Anderson *et al.*, 2009; Kratz, Sander, Brickell, Lange & Carlozzi, 2015; Kreutzer, Gervasio & Camplair, 1994a; Kreutzer, Gervasio & Camplair, 1994b; Livingstone & Brooks, 1985 – see Ennis, Rosenbloom, Canzian & Topolovec-Vranic, 2013 for overview), there has been more consensus regarding the qualitative differences (i.e. nature and type of experiences). For example, parents described returning to their previous parental and caregiver roles (Serio *et al.*, 1995; Wood, Liossi & Wood, 2005), whereas partners also acknowledge adopting parental roles and

experience loss of their peer-based, reciprocal relationships (Gervasio & Kreutzer, 1997; Lezak, 1988). Partners also sometimes experience increased financial strain (Gervasio & Kreutzer, 1997) and reduced mutual child-parenting support (Blais & Boisvert; Perlesz *et al.*, 1999), where their parent counterparts may hold shared responsibility (e.g. providing care and financially). Parents have also been suggested to have long standing, well-established support networks which can buffer their negative experiences (Panting & Merry, 1972). With these in mind, authors suggest that the experience may be more difficult and stressful for partners (e.g. Liss & Willer, 1990; Perlesz *et al.*, 1999).

Relationship dissolution and breakdown, often recognised as marital instability and divorce, is widely documented in the literature following a TBI and has been suggested to increase with time post-injury (Wood & Yurdakul, 1997). Relationship breakdown has been estimated to range from 15% to 54% following TBI (Anderson-Parente, DeCasare & Parente, 1990; Kreutzer, Marwitz, Hsu, Williams & Riddick, 2007; Kreutzer, Sima, Marwitz & Lukow, 2016; Wood & Yurdakul, 1997) compared with approximately 42% in the general population (Office for National Statistics, 2012). Discrepancies between prevalence rates may be the result of differences in methodologies (e.g. study objectives, designs) and heterogenic samples (e.g. differences in TBI severity, time since injury). Relationship instability raises issues for the family's outlook and can have detrimental implications for the individual's long-term placement and for services and the provision of care (Godwin, Kreutzer, Arango-Lasprilla & Lehan, 2011). In attempts to illuminate understanding of relationship dissolution, authors have suggested drawing on literature around relationship quality. This may be increasingly important as estimates of divorce and separation have been lower in the recent TBI literature, which is also likely to be in spite of the high levels of relationship dissatisfaction (Godwin *et al.*, 2011). Several authors (Lezak, 1988; Wood, 2006) have described the 'moral dilemma' that couples experience, particularly for partners, as they can find themselves in situations where they are increasingly reluctant to engage in divorce due to feelings of responsibility, guilt, fear and/or social condemnation. This can result in couples remaining in unhappy relationships.

The concept of 'relationship quality' seems to lack specificity and is often inconsistent within the literature (e.g. relationship satisfaction, relationship adjustment, etc). This

has increased variation in the research methodology applied (e.g. subsequent outcome measures) and resulted in a wide range around factors influencing relationships following TBI and vice versa (i.e. what it influences) (Blais & Boisvert, 2005). Examples of factors include: financial difficulties, injury severity, injury-related consequences (e.g. communication difficulties, changes in personality), presence of children, available support for partners, coping strategies (i.e. attributions), insight, and role changes (see Blais & Boisvert, 2006; and Perlesz *et al.*, 1999). Decreases in marital cohesion and increases in marital conflict have also been noted (e.g. Maitz, 1990, 1991).

Although a promising start to understanding the concept of relationship quality, the majority of studies only sampled either the person with TBI or their partner and have not explored the impact on the dyad, which ignores the possible interactional and relationship processes, as well as limiting understanding to only one perspective (Godwin *et al.*, 2011). Consequently, more a systemic and dyadic approach has been called upon by researchers (e.g. Blais & Boisvert, 2005; Godwin *et al.*, 2011). To the authors' knowledge, there has not been a systematic review that has explored the current state of the evidence-base around couples' experiences and relationship quality following TBI from a dyadic perspective. Previous reviews have generally take a narrative approach and have included both dyadic and non-dyadic studies together (e.g. Blais & Boisvert 2005; Godwin *et al.*, 2011; Liss & Willer 1990). In summary, gaining a better understanding of the current TBI evidence-base around couples' experiences and relationships from a dyadic perspective may highlight the individuals and couples' unique individuals' experiences and interactional process, which may provide insight into their needs and provide some provisional recommendations for services (i.e. for the individual with TBI, their partner, or jointly).

### 1.1. *Aim*

The main aim of this mixed-method synthesis review was to provide an overview of the current state of the research evidence base exploring couples' experiences and relationship quality from a dyadic perspective; and, where possible, provisional considerations for future research and/or clinical practice are included.

## 2. **Methodology**

This mixed-method synthesis review was guided by the Meta-analysis of Observational Studies in Epidemiology (MOOSE; Stroup *et al.*, 2000) and the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ; Tong, Flemming, McInnes, Oliver & Craig, 2012) reporting checklists, to increase reporting transparency of the quantitative observational and qualitative synthesis respectively. The Joanna Briggs Institute Mixed Methods Systematic Reviews manual (Pearson *et al.*, 2014) was also consulted where applicable.

The review protocol was published on the PROSPERO website (CRD42018087937; Chadwick, 2018).

### 2.1. Design

Although mixed-method syntheses aim to meaningfully integrate findings from quantitative and qualitative studies, there has been criticism around the acceptability or feasibility of translating studies from the different paradigms. It has also been questioned whether it is possible to synthesise qualitative findings based on their differing, and sometimes conflicting, philosophical foundations (Booth *et al.*, 2016). It has been described that for some researchers, particularly historically, this creates underlying and insurmountable incompatibilities for translating quantitative and qualitative studies together (Dixon-Wood *et al.*, 2005). These views have possibly unintentionally limited the number of reviews that have included both qualitative and quantitative research. Recently the shift in perspective has steadily increased recognition of the depth and richness of qualitative data, as well as the use of qualitative research to complement quantitative findings or answer and explore questions or areas that cannot be captured purely quantitatively (Gough, 2015; Harden & Thomas, 2008). Increased publications of qualitative studies and greater clarity around qualitative synthesis methodologies has resulted in an increase in qualitative and mixed-method syntheses (Dixon-Wood *et al.*, 2005; Gough, 2015; Harden & Thomas, 2008).

The approach used within this review was consistent with a segregated mixed-method approach (Joanna-Briggs; Sandelowski, Voils & Barroso, 2006), which has been suggested to be suitable for the reciprocal translation of concepts between qualitative

and quantitative research. Due to the segregated approach, the RETREAT criteria were consulted to decide the appropriate synthesis approach for the qualitative studies (Booth *et al.*, 2016). For more information see [Table 1](#). Meta-ethnography was identified as the chosen analysis for the qualitative synthesis (Noblit & Hare, 1988).

**Table 1. RETREAT framework criteria (Booth *et al.*, 2016)**

Review question	Explanatory question: to provide an overview of the current state of the evidence-based research exploring couples' experiences and relationship quality from a dyadic perspective
Epistemology	Critical realist
Time/timeframe	Rapid, but thorough
Resources	University funded, small team
Expertise	Primary researcher: novice-intermediate qualitative and systematic research skills. Access to qualitative research specialists and clinical experts for design of the strategy.
Audience and purpose	Academic and practitioner
Type(s) of data	Mixed-methods: three quantitative; and five qualitative studies included.
Choice of method	Meta-ethnography

## 2.2. Search strategy

A systematic computerized search was conducted in Embase, MEDLINE, PsycINFO, CINAHL and ProQuest dissertations databases on the 19<sup>th</sup> January 2018. The same search was conducted on 12<sup>th</sup> June 2018 to include any new studies. Variations of following derivative terms were used to search the databases: "traumatic brain injury"; AND couples OR partners OR marit\* OR dyad\* OR husband\* OR wife OR wives OR "Significant Other\*" OR spouse\* OR cohabitation OR marriage (See [Table 2](#) for detailed database search strategies). The applied search terms were selected in collaboration with clinical experts in the field and university librarians. Manual hand searches of the retrieved studies and other key reviews (e.g. Godwin *et al.*, 2011; Liss & Willer, 1990; Blais & Boisvert, 2005) were used to capture any publications not included in the systematic database search. No restrictions were imposed based on date of publication or the type of study included; however, unpublished studies (e.g.,

dissertations) were not included if they had subsequently been published to prevent duplication.

### 2.3. *Selection criteria*

[Table 2](#) provides a detailed overview of the inclusion and exclusion criteria using the SPIDER tool (Cooke, Smith & Booth, 2012). Studies that met the following general criteria were included: (i) studies that explored couples' dyadic experiences and relationships following TBI; (ii) studies that sampled dyad-couples where one partner of the dyad had sustained a TBI in their adulthood; (iii) studies that involved both partners of the dyad as active participants; and (iv) unpublished or peer-reviewed published qualitative, quantitative or mixed-methods studies.

**Table 2. Inclusion and exclusion criteria utilising the SPIDER tool (Cooke, Smith & Booth, 2012) and database search strategies details**

	Inclusion	Exclusion
Sample	Dyad-couples where one partner of the dyad has experienced a TBI, which was sustained in adulthood	Studies involving only one member of the dyad (e.g. only person with the TBI or their spouse/partner) Studies involving family members (involving parents, children or other family members) without separate partner-dyad analyses Studies including individuals who have suffered from other forms of neurological conditions (other than TBI) or do not provide separate analysis for TBI participant couples Paediatric TBI
Phenomenon of Interest	Relationship quality and experiences following TBI <i>Relationship quality</i> is an umbrella term that encompasses couples' evaluations of different aspects relating to their intimate interpersonal relationships (Fincham & Bradburg, 1987; Godwin <i>et al.</i> , 2011)	Studies that explore aspects of relationship stability or sexuality (without exploration of relationship quality)

Design	<p><i>Quantitative</i>: measure of relationship quality provided separately for both partners of the dyad or analysis conducted on comparing ratings provided by person with TBI and their partner</p> <p><i>Qualitative</i>: data collected via interview must be provided for both partners of the dyad (e.g. individual person with TBI-partner interviews or joint interviews)</p>	
Evaluation	<p>Dyad-couple experiences</p> <p>Comparison group: not deemed essential to research question</p> <p>Interventions studies that focused on the couple's experiences post-injury will be included if pre-treatment relationship findings are provided</p>	<p>Intervention studies that do not provide pre-treatment relationship findings</p>
Research Type	<p>Studies that utilised qualitative, quantitative or mixed-methods design</p> <p>Unpublished and peer-reviewed published studies</p>	<p>Unpublished studies (e.g., dissertations) that had been subsequently been published</p> <p>Case studies</p> <p>Literature reviews, conference abstracts/posters, books and book chapters or letters to editors</p> <p>Articles published in a language other than English</p>
Search details CINAHL Plus (from 1937)	<p>S1 (MM "Brain Injuries+") TI ( couples or partners or marit* or dyad* or husband* or wife or wives or "Significant Other*" or "spouse*" or cohabitation or marriage ) AND AB ( couples or partners or marit* or dyad* or husband* or wife or wives or "Significant Other*" or "spouse*" or cohabitation or marriage ) AND MW ( couples or partners or marit* or dyad* or husband* or wife or wives or "Significant Other*" or "spouse*" or cohabitation or marriage )</p> <p>S2</p>	



	S3	S1 AND S2
Search details	1	(exp *traumatic brain injury/)
Embase Classic		(couples or partners or marital* or dyad* or husband* or
+ Embase (from	2	wife or wives or "Significant Other*" or spouse* or
1947 to 2018		cohabitation or marriage).ab,hw,kw,ti.
January 04)	3	1 AND 2
Search details	1	exp *Brain Injuries, Traumatic/
Ovid MEDLINE		(couples or partners or marital* or dyad* or husband* or
(R) Epub Ahead	2	wife or wives or "Significant Other*" or spouse* or
of Print, In-		cohabitation or marriage).ab,hw,kf,ti.
Process & Other		
Non-Indexed		
Citations and		
Ovide	3	1 AND 2
MEDLINE(R)		
without		
Revisions 2013		
to Daily Update		
Search details		(ab("traumatic brain injury") OR su("traumatic brain injury") OR
ProQuest		ti("traumatic brain injury")) AND (ab(couples OR partners OR
Dissertations &		marital* OR dyad* OR husband* OR wife OR wives OR
Theses		"Significant Other*" OR spouse* OR cohabitation OR
Database		marriage) OR su(couples OR partners OR marital* OR dyad*
(PQDT)		OR husband* OR wife OR wives OR "Significant Other*" OR
		spouse* OR cohabitation OR marriage) OR ti(couples OR
		partners OR marital* OR dyad* OR husband* OR wife OR wives
		OR "Significant Other*" OR spouse* OR cohabitation OR
		marriage))
Search details	1	exp *Traumatic Brain Injury/
PsychINFO		(couples or partners or marital* or dyad* or husband* or
1806 to January	2	wife or wives or "Significant Other*" or "spouse*" or
Week 1 2018		cohabitation or marriage).ab,hw,id,ti.
	3	1 AND 2

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#### 2.4. *Data collection and extraction*

The search results from the separate databases were combined and duplicates were removed. Subsequently, the titles and abstracts of the search results were independently screened for suitability by two members of the research team (NC and AC). The first researcher (NC) screened all search results, whereas the second researcher (AC) screened 20% of all search results, which were randomly selected utilising an automatized computerised number generator. Following the initial review of titles and abstracts, the researchers further reviewed the full texts of the remaining, non-excluded studies for suitability against the selection criteria. Disagreements between researchers were addressed through direct discussion between the researchers in the first instance and where a consensus was not met through discussion, this was discussed with a third researcher (EN).

#### 2.5. *Quality assessment*

The quality of all included studies was independently assessed by members of the research team (i.e. NC and AC or NC and SB, for quantitative and qualitative respectively). Quantitative studies were reviewed using Appraisal tool for Cross-Sectional Studies (AXIS; Downes, Brennan, Williams & Dean, 2016), whereas qualitative studies were assessed using the Joanna Briggs Institute's Critical Appraisal Checklist for Qualitative Research (JBI-QARI; Joanna Briggs Institute, 2014). Disagreements around quality ratings were initially addressed through discussion between the two analysts. If a consensus was not met, a third researcher was employed (EN). The quality rating assessments were not used for the purpose of excluding studies, but rather to describe what had been observed (Hannes, 2011).

##### 2.5.1. *Appraisal tool for Cross-Sectional Studies (AXIS; Downes et al., 2016)*

AXIS is a relatively new appraisal tool and was developed after authors recognised there was no appraisal tool that suitably assessed the quality of cross-sectional studies (Downes *et al.*, 2016). Although other tools had been previously used for this purpose (e.g. CASP; Critical Appraisal Skills Programme, 2018), their validity has been questioned (see Downes *et al.*, 2016). AXIS consists of 20 items that assess the

study's aims, sample (e.g. size, sample selection, etc), use of measures and data analysis for quality and potential risks of bias. The items include a mixture of reporting criteria and quality assessment questions. AXIS has also been previously used in other healthcare mixed-method synthesis reviews (e.g. Wong, McAuley & Trinh, 2018). See [Appendix 2](#).

#### *2.5.2. Joanna Briggs Institute's Critical Appraisal Checklist for Qualitative Research (JBI-QARI; Lockwood, Munn & Porritt, 2015)*

The use of critical appraisal tools for assessing qualitative research is subject to ongoing debate (e.g. Booth, 2016; Dixon-Woods *et al.*, 2006), which has resulted in variability among use of tools within the systematic and synthesis review literature (Dixon-Wood *et al.*, 2005). The NHS CRD guidance (Khan, Ter Riet, Glanville, Sowden & Kleijnen, 2001) encourages the use of structured approaches to assess the quality of qualitative studies for reviews, however the guidance recognises the lack of clear guidance and consensus around how this should be undertaken. The JBI-QARI appraisal tool was used in this mixed-method synthesis as the aims seemed consistent with the qualitative data synthesis approach (i.e. meta-ethnography) and emphasized evaluation of the studies quality content, rather than method.

The JBI-QARI is a well-established tool that has been used extensively within qualitative systematic reviews (e.g. Munn & Jordan, 2011). It consists of 10-items that assess the theoretical framework, methodological approach, data collection and analysis, as well as the representation of the voices or meanings of study participants. In a review comparing three different qualitative critical appraisal tools, the JBI-QARI was deemed more sensitive to aspects of validity (e.g. interpretative, theoretical, and evaluative validity) and had increased value due to its focus on congruity compared with the other tools (Hannes, Lockwood & Pearson, 2010). See [Appendix 3](#).

#### *2.6. Interrater analysis*

Interrater agreement on rating of the inclusion and exclusion criteria and critical appraisal tools were analysed using Cohen's kappa (as described by Landis & Koch, 1977) in SPSS version 11.

## 2.7. Qualitative synthesis

Meta-ethnography was developed by Noblit and Hare (1988) with the aim to provide an approach for translating concepts from individual studies to form a 'whole' (Strike and Posner 1983), as opposed to aggregating data. This was initially developed to synthesize ethnographical studies, however has been successfully applied to non-ethnographical qualitative syntheses (Barnett-Page & Thomas, 2009; Britten *et al.*, 2002; Campbell *et al.*, 2012) and mixed-method syntheses (Harden, 2010). Meta-ethnography uses an interpretive approach, which explicitly attempts to preserve 'the interpretive properties of the primary data' (p.48; Dixon-Wood *et al.*, 2005) and has also been found to be suitable for synthesising small, discrete number of studies (Noblit & Hare, 1988). Meta-ethnography produces three main, and not necessarily mutually exclusive, types of syntheses: (1) reciprocal (e.g. looking at commonalities), (2) refutational (e.g. exploring difference and contradictions) and/or (3) line of argument translations (Noblit and Hare, 1988).

This synthesis followed the seven steps as outlined by Noblit and Hare (1988) and recommendations in recent worked examples (e.g. Britten *et al.*, 2002; Britten & Pope, 2011; Campbell *et al.*, 2003). See [Figure 1](#) for overview of metaethnography steps. The meta-ethnography in this synthesis involved firstly, deciding to look at TBI and couple's relationships and experiences following TBI (*Getting started* and *Deciding what is relevant to the initial interest*; and conducting quality assessment). This stage also involved forming the search strategy, systematically searching the literature for eligible studies and assessing quality of the studies. This was followed by becoming familiarised with the eligible studies (*Reading the studies*) and looking for possible overlapping concepts or themes, which were placed in a grid using a Microsoft Excel Spreadsheet for ease of comparison across all studies (*Determining how the studies are related* – See [Table 6](#) for Summary grid of key concepts and themes translated across studies). Studies were *translated into one and another*, which suggested the synthesis resembled a reciprocal and refutational translation. Finally, *Synthesising translations* and *Expressing the synthesis* are presented in the discussion.

**Figure 1. Noblit and Hare's (1988) metaethnography steps**

Seven steps of metaethnography:

1. *Getting started*
2. *Deciding what is relevant to the initial interest*
3. *Reading the studies*
4. *Determining how the studies are related*
5. *Translating the studies into one another*
6. *Synthesising translations*
7. *Expressing the synthesis*

### 3. Results

#### 3.1. Search results

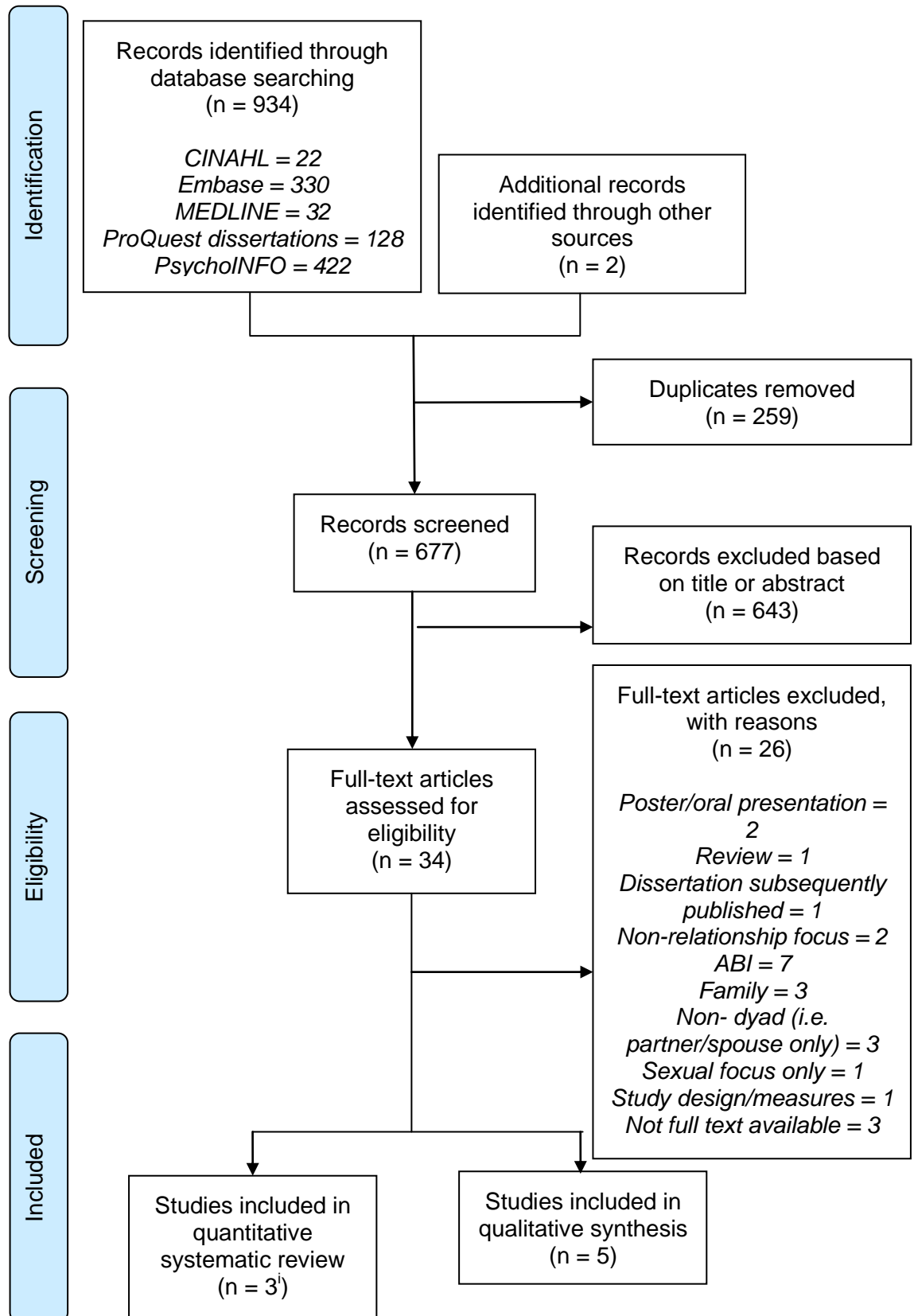
Of the 934 studies identified by the original systematic computerised search, two quantitative studies, one mixed-method study and five qualitative studies were eligible and were included in this mixed-method synthesis (for more details refer to [Figure 2](#) PRISMA flowchart). Only the quantitative findings of the mixed-method study met the inclusion criteria and were included as part of this synthesis. One eligible dissertation thesis was excluded as it had been subsequently published (see [Appendix 1](#)). The eligibility criteria yielded a moderate agreement when screening 30% of all studies (across the screening and eligibility stage) by two researchers,  $\kappa = .555$ ,  $p < .0005$ .

#### 3.2. Study characteristics

The sample sizes of studies ranged from three to 47 couples with a total of 176 couples across studies (107 couple participated in the quantitative studies and 69 in the qualitative). The majority of studies included participants with TBI from both genders (5/8) and the remained (3/8) included only males with TBI. The sexual orientation of the samples varied: three included only heterosexual couples, three included both heterosexual and same-sex couples, whereas the sexual orientation in two samples were unclear for two studies. The samples' injury severities ranged within the studies: two included all levels of severity (2/8), one that focused on mild TBI, three included only moderate to severe TBI and two remain unclear. The time since injury across studies ranged from 0.3–25 years. A range of quantitative relationship outcome measures were administered: Revised Dyadic Adjustment Scale, Dyadic Adjustment Scale and a non-standardised relationship change questionnaire. Similarly, the qualitative designs varied: two grounded theory, one IPA, one content analysis and one nominal process group technique. The majority of studies were conducted outside of the UK; only two quantitative studies were conducted in the UK. Summary of study characteristics is provided in [Table 3](#).

The relatively small sample sizes and significant heterogeneity of the quantitative studies limited the feasibility of conducting a meta-analysis.

**Figure 2. PRISMA 2009 Flow Diagram for systematic search**



<sup>i</sup> inclusive of one mixed-method study

### 3.3. Methodological quality of included quantitative studies

There was substantial agreement between the researchers' ratings on AXIS (Downes *et al.*, 2016),  $\kappa = .899$ ,  $p < .0005$ . Overview of the agreed AXIS ratings is provided in [Table 4](#). The quality of the included quantitative studies was mixed. Methodological quality was variable across studies, particularly with regards to providing information about sample-related variables (e.g. no power analyses were provided to justify the sample sizes). Further concerns were raised around possible sampling biases created by the recruitment procedures (e.g. self-selection from a single site) and also the lack of information around non-responders. Only Gosling and Oddy (1999) reported the response rate in their study (42%), whereas Wood and Williams (2012) provided brief information about the number of participants who met the inclusion criteria for their sample. Compared with the other two studies, the quality and transparency of reporting in Gosling and Oddy's (1999) study was limited, which had implications for determining some of the items' quality ratings (e.g. conclusion around the quantitative findings were not included in the discussion). This may have been due to journal word limit restrictions when attempting to describe both the quantitative and qualitative findings in detail, or possibly due to limited awareness or availability of well-established reporting guidelines at the time of the study's publication.

### 3.4. Methodological quality of included qualitative studies

There was a moderate agreement between the researchers' ratings on the JBI-QARI (Joanna Briggs Institute, 2014),  $\kappa = .548$ ,  $p < .0005$ . Overview of the agreed JBI-QARI ratings is provided in [Table 5](#). Generally, the quality of the qualitative studies rated by JBI-QARI was variable. All of the studies were deemed as achieving aspects of congruity (e.g. congruity between philosophical perspective and methodology); however, there was less consistency within the studies to explore potential biases created by the researchers' own cultural or theoretical standpoints or the bidirectional processes between the researcher and the study itself. For example, only one study (Jacobsmeier Werner, 2016) provided some information about the authors' own cultural and theoretical stance. Gill *et al.* (2011) and Hyatt *et al.* (2015) mention that the researcher could have an influence on the data within their studies' limitations, however



did not seem to explicitly consider specific examples of potential biases on the findings. Positively, all studies, apart from Willer *et al.* (1991), attempted to adequately represent their participants' voices by providing quotes and illustrations from the data. The exact method used by Willer *et al.* (1991) to translate the final themes within their study was unclear and therefore raised uncertainty around how representative the final themes were to the participants' voices. Additionally, not all studies stated whether or how ethical approval was gained for their studies.

**Table 3. Characteristics of included studies**

<b>Authors, year, country</b>	<b>Participants/sample source M (SD)</b>	<b>Control M (SD)</b>	<b>Design (design, method, measures of relationship)</b>	<b>Summary of aims</b>
Gosling & Oddy, 1999 UK	18 couples Age = n/a Length of relationship = 16.2 years (9.4) Time since injury = 4.1 years (1.9)  <i>People with TBI:</i> Age = 42.1 years (12.5) 100% males  <i>Partners:</i> Age = 39.2 years (11.1) 0% males	-	Mixed method - Quantitative Questionnaires: Golombok and Rust Inventory of Marital State (GRIMS) and a six-item relationship change questionnaire t-test (and correlation)	<i>Aims:</i> to explore the quality of couples' marital and sexual relationship 1-7 years post-injury

Authors, year, country	Participants/sample source M (SD)	Control M (SD)	Design (design, method, measures of relationship)	Summary of aims
Gill, Sander, Robins, Mazzei, & Struchen, 2011 USA	18 Outpatient community couples Age = n/a Relationship <5 years = 44.4% (range: 0.5-3.5) Relationship >5 years = 55.6% (range: 6.0-36.0) Time since injury = 4.78 years (n/a)  <i>People with TBI:</i> Age = 38.5 years (n/a) 66.7% male  <i>Partners:</i> Age = 39.4 years (n/a) 27.8% male	-	Qualitative: grounded- theory approach Individual semi-structured interviews	<i>Aims:</i> To explore couple's experiences of intimacy following TBI

Authors, year, country	Participants/sample source M (SD)	Control M (SD)	Design (design, method, measures of relationship)	Summary of aims
Hyatt, Davis & Barroso, 2015 USA	9 couples Age = n/a Length of relationship = 9.7 years (8.8) Time since injury = 10.8 years (n/a)  <i>People with TBI:</i> Age = 33.4 years (7.5) 88.9% male Mild TBI = 100%  <i>Partners:</i> Age = 33.9 years (9.2)	-	Qualitative: grounded theory Semi-structured interviews: Nine conjoint, nine with people with TBI and nine with partners	<i>Aims:</i> to explore couples' reintegration experience following a combat-related mTBU

Authors, year, country	Participants/sample source M (SD)	Control M (SD)	Design (design, method, measures of relationship)	Summary of aims
Jacobsmeier Werner, 2016 USA	3 couples Age = n/a Length of relationship = 34.3 years (n/a) Time since injury = 100% >2 years  <i>People with TBI:</i> Age=n/a 66.7% male  <i>Partners:</i> Age=n/a 33.3% male	-	Qualitative: Interpretive phenomenological analysis Two semi-structured interviews	<i>Aims:</i> to explore couples' attachment relationships following TBI

Authors, year, country	Participants/sample source M (SD)	Control M (SD)	Design (design, method, measures of relationship)	Summary of aims
Kreutzer, Sima, Marwitz & Lukow, 2016 USA	42 couples Age: n/a Length of relationship = 12.0 years (n/a) Time since injury = 2.2 years (2.93)  <i>People with TBI:</i> Age = 49.8 years (n/a) Mild TBI = 48% Moderate/severe TBI = 48% <sup>a</sup>  <i>Partners:</i> Age = 48.2 years (13.26) 29% male	-	Quantitative Questionnaires: Marital Status Inventory (MSI) and Revised Dyadic Adjustment Scale (RDAS) Multivariate logistic regression model	<i>Aims:</i> to identify predictors of marital instability from a couples' perspective

Authors, year, country	Participants/sample source M (SD)	Control M (SD)	Design (design, method, measures of relationship)	Summary of aims
Layman, Dijkers & Ashman, 2005 USA	8 couples Age = (n/a) Length of time living together = 39.6 years (n/a) Time since injury = 6.88 years (n/a)  <i>People with TBI:</i> Age = 71.1 years (n/a) 37.5% male Mild TBI = 50% Moderate/severe TBI = 50%  <i>Partners:</i> Age = 70.4 years (n/a) 75% male	5 couples Age = n/a Length of time living together = 26 Time since event = 7.25  <i>People who experienced the event:</i> Age = 67.6 60% male  <i>Partners:</i> Age = 61.6 20% male	Qualitative: content analysis approach Individual semi-structured interviews: telephone and face-to-face	<i>Aims:</i> to explore older couples' relationships following TBI

Authors, year, country	Participants/sample source M (SD)	Control M (SD)	Design (design, method, measures of relationship)	Summary of aims
Willer, Allen, Liss, & Zicht, 1991 Canada	31 couples <sup>b</sup> Age range = 21-61 years Length of marriage = 14.0 years (n/a) Time since injury = 1.5-33 years (median = 4)  <i>People with TBI:</i> Age = n/a 64.5% male Severe TBI = 93.3% <sup>c</sup>  <i>Partners:</i> Age = n/a n/a	-	Qualitative: Process nominal group technique Eight structured, small- group discussions coordinated by a member of the research team: female spouses with TBI; non-injured male spouses; male spouses with TBI; and non-injured female spouses	<i>Aims:</i> to explore the types of problems and coping strategies reported by couples following a severe head injury



Authors, year, country	Participants/sample source M (SD)	Control M (SD)	Design (design, method, measures of relationship)	Summary of aims
Williams & Wood, 2012 UK	47 post-acute couples Age = n/a Length of relationship = 16.4 years (13.50) Time since injury = 2.71 years (1.64)  <i>People with TBI:</i> Age = 49.9 years (13.32) 78.7% males Mild TBI = 0% Moderate/severe TBI = 100%  <i>Partners:</i> n/a	-	Quantitative Questionnaires: Index of Marital Satisfaction (IMS) and Dyadic Adjustment Scale (DAS) Paired sample t-test	<i>Aims:</i> to explore relationship quality and satisfaction of couples following TBI. To explore the impact of alexithymia on these.

<sup>a</sup> Unable to identify for two cases

<sup>b</sup> Three couples started relationship after brain injury

<sup>c</sup> Injury severity unavailable for one individual

**Table 4. Critical appraisal results for included quantitative studies using the AXIS (Critical) Appraisal Checklist**

Study	Introduction	Methods								
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Gosling & Oddy, 1999	Y	Y	U	Y	U	U	U	Y	U	U
Kreutzer, Sima, Marwitz & Lukow, 2016	Y	Y	U	Y	U	U	U	Y	Y	Y
Williams & Wood, 2012	Y	Y	U	Y	U	U	U	Y	Y	Y

Ratings: Y = yes; N = no; U = unclear

Study ( <i>continued...</i> )	Results					Discussion			Other	
	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20
Gosling & Oddy, 1999	U	U	N	U	Y	U	U	Y	N	Y
Kreutzer, Sima, Marwitz & Lukow, 2016	Y	Y	U	U	Y	Y	Y	Y	N	Y
Williams & Wood, 2012	Y	Y	U	U	Y	Y	Y	Y	N	Y

Ratings: Y = yes; N = no; U = unclear

**Table 5. Critical appraisal results for included qualitative studies using the JBI-QARI Critical Appraisal Checklist**

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Gill, Sander, Robins, Mazzei, & Struchen, 2011	Y	Y	Y	Y	Y	N	U	Y	U	Y
Hyatt, Davis & Barroso, 2015	Y	Y	Y	Y	Y	N	U	Y	Y	U
Jacobsmeier Werner, 2016	Y	Y	Y	Y	Y	U	Y	Y	U	U
Layman, Dijkers & Ashman, 2005	Y	Y	Y	Y	Y	N	N	Y	N	Y
Willer, Allen, Liss, & Zicht, 1991	Y	Y	Y	U	Y	N	N	U	N	U

Ratings: Y = yes; N = no; U = unclear

**Table 6. Summary grid of key concepts and themes translated across studies**

Concepts and themes	Gill <i>et al.</i> (2011)	Hyatt, Davis & Barroso (2015)	Jacobsmeier Werner (2016)	Layman, Dijkers & Ashman (2005)	Willer <i>et al.</i> (1991)
<b>Couples' perceptions of TBI consequences</b>	x	x	x	x	x
<b>Changes to the couples' relationship dynamics</b>					
Role changes	x	x	x	x	x
Dependence	x		x	x	x
Communication	x	x	x	x	
Sexual relationship	x		x	x	x
Changing perspectives and acceptance	x	x	x	x	x
<b>Dealing with changes (Coping strategies)</b>	x	x	x	x	x
<b>Other contextual factors</b>					
Services			x		x
The wider family and system	x	x	x	x	x
Separation	x		x		
Non-TBI factors	x	x	x	x	
Commitment and love	x		x	x	

### 3.5. *Quantitative studies and relationship quality*

A discrete number of quantitative studies explored relationship quality from a dyadic perspective. Although Kreuter *et al.*'s (2016) findings suggested that the couples did not report significantly elevated distressed relationships after a TBI, approximately half of participants with TBI and their partners described the quality of their relationships as poor. It was also suggested that higher levels of reported distress were significantly associated with increased relationship instability, however this was not the case for all couples (e.g. some stable couples also reported high levels of distress). Unfortunately, no other dyad study has been conducted to verify these findings. Meanwhile, studies that compared individuals with TBI and their partner's ratings of relationship quality suggested that partners generally experience significantly more dyadic dissatisfaction and overall poorer relationship adjustment than the person with a TBI (Gosling and Oddy, 1999; Williams and Wood, 2012). Williams and Wood's (2012) study also suggested that people with TBI are less likely to report relationship difficulties than their partners.

### 3.6. *Qualitative studies and synthesizing the translations*

Synthesised findings were identified under the following translation headings: couples' perceptions of TBI consequences; changes to the couples' relationship dynamics; dealing with changes (Coping strategies); and other contextual factors. See [Table 6](#) for summary of key concepts and themes translated across studies.

#### 3.6.1. *Couples' perceptions of TBI consequences*

Couples across all studies (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991) spoke about the different types of TBI consequences. These included physical changes, cognitive difficulties, emotional and behavioural changes (e.g. experience and expression of emotions), as well as perceived changes in personality.

Physical (e.g. pain) and cognitive (e.g. difficulties with attention, processing speed and executive functioning) changes were described as having an influence on the person

with TBI's ability to carry out and participate in activities (such as roles at home or sexual activities) (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Willer *et al.*, 1991). Furthermore, these were portrayed as limiting or acting as barriers to the person with the TBI expressing intimacy, such as physical and spontaneous acts of affection (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016). For example, '*one man told of no longer playfully sneaking up on his partner and giving her a hug*' (p.60; Researchers) (Gill *et al.*, 2011).

Changes in personality, behaviours and emotion recognition, expression and management were also recognised within couples. Most notably, difficulties with temper and mood swings (Jacobsmeyer Werner, 2016; Willer *et al.*, 2011). Partners described feeling unprepared for these types of consequences and as though they were often '*walking on eggshells*' (p.304; Partner) (Hyatt, Davis & Barroso, 2015). For some, this resulted in feelings of bewilderment and helplessness (Willer *et al.*, 1991). In one study, these changes were perceived by the partners as changing the person with TBI's very '*personhood*' (p.61; Researcher) (Gill *et al.*, 2011). On the whole, partners had mixed reactions to the changes in emotional and behavioural expression. Some felt embarrassed by the person with TBI's more challenging behaviours, whereas others described more positive changes and felt that the person with TBI had become more emotionally involved in their families since the TBI (Gill *et al.*, 2011). Emotional changes reported by people with TBI included problems with loneliness and depression (Gill *et al.*, 2011) and increased feelings of insecurity (Willer *et al.*, 1991). Partners in another study reported that the individuals with TBI became more overprotective (Willer *et al.*, 1991).

Both individuals referred to reductions in their self-confidence and self-esteem due to the changes following TBI (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Willer *et al.*, 1991). People TBI described these as a result of their loss of autonomy and independence (Willer *et al.*, 1991), as well as in relation to their performance as sexual partners (e.g. '*Sex is kind of difficult, because I cannot perform with her like I choose to, like I want to*'; p.61; Person with TBI) (Gill *et al.*, 2011) and their ability to fulfilling traditional social roles (Gill *et al.*, 2011). Meanwhile partners expressed feelings of inadequacy and helplessness, which were sometimes associated with their ability to care for person with TBI or sometimes in response to the person with TBI's mood

swings (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Willer *et al.*, 1991). Some couples specifically disclosed feelings of inadequacy to preserve their relationship (Gill *et al.*, 2011).

People with TBIs also expressed frustration due to limitation placed on them by their TBI (Willer *et al.*, 1991) and also feelings of guilt (Jacobsmeyer Werner, 2016) that may have been associated with feeling as though they were a burden to their family or were unable to make their partners happy (Hyatt, Davis & Barroso, 2015). This concerned one person with TBI in Jacobsmeyer Werner's (2016) as he thought his partner may leave him. A couple of partners in the same study expressed ongoing hypervigilance and increased concerns around the person with TBI's wellbeing and safety (Jacobsmeyer Werner, 2016).

### 3.6.2. *Changes to the couples' relationship dynamics*

*Role change.* The definition of role changes was taken from Layman, Dijkers and Ashman (2005), who described this as '*changes in participation in partnership activities including decision-making, household responsibilities and financial management*' (p.915; Researcher). Aspects of these were acknowledged across studies (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991). Most of data richness regarding role change was based on the partners' experiences and perspectives, however the people with TBI in Gill *et al.*'s (2011) sample acknowledged difficulties and feelings of sadness in letting go of their previous roles.

Following TBI, many partners assumed some form or aspect of the caregiving role, which ranged from providing physical or emotional support to adopting the role as a case manager (Hyatt, Davis & Barroso, 2015). This required significant renegotiate of roles (Hyatt, Davis & Barroso, 2015) and was depicted as a '*juggling act*' (p.62; Researchers) (Gill *et al.*, 2011). Partners often compared their post-injury relationship to one of a partner-child (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005), which for some created dyad conflict as well as internal conflict within the partner, associated with feelings of being controlling (Jacobsmeyer Werner, 2016). Interestingly some of the reactions from the people with TBI mirrored feelings of

being controlled, which were sometimes perceived as unwarranted; however, not all people with TBI perceived this negatively and some expressed appreciation towards the increased concern and involvement of their partners (Layman, Dijkers & Ashman, 2005). Partners conveyed both positive and negative responses to their role changes. For example, participants across two studies highlighted the challenges presented by the reduction in mutual reciprocity and queried if the demands were worth the return (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016). Fortunately for some, this dynamic changed over time and allowed the relationship to be less one-sided (Jacobsmeyer Werner, 2016).

Several studies reported changes to the financial, 'bread winning' roles for people with TBI which often resulted in increased financial strain for couples and for some meant that the partner had to take on work or increase their hours (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991). This was suggested to be stressful for both individuals for different reasons. For example, partners may struggle with the increased burden, as well as concern around leaving the person with the TBI alone for a significant period of time. The increased responsibility generally impacted on the amount of time available for couples to spend together, which was claimed to be particularly important for enforcing the couples bond by Gill *et al.* (2011) and Jacobsmeyer Werner (2016).

*Dependence.* Changes in the person with TBI's level of dependence and autonomy were often described within dyad-couples (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991). They described increased reliance around finances, physical and social support, decision-making and functional tasks such as driving. Some partners described difficulties in determining and creating a balance for the people with TBI to receive support from them, whilst also facilitating the person with TBI's independence (Layman, Dijkers & Ashman, 2005).

Layman, Dijkers & Ashman (2005) highlighted a theme associated with couples' mutual dependence coined as '*interdependence*'. Aspects of this concept were also described in Jacobsmeyer Werner (2016) and Willer *et al.* (1991). Generally, couples gave mixed responses to their perceived levels of interdependence after brain injury; some reported no change in their ability to rely on each other for support, others described



reductions and some stated their ability to rely on each other had increased. The majority of partners, however, noticed a reduction in their ability to rely emotionally on the person with TBI, as well as overall changes in their reciprocal companionship with that person (Willer *et al.*, 1991).

*Communication.* Various aspects of changes in the couples' communication styles and quality were reported across all the studies (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991), with partners generally acknowledging fluctuations over the course of recovery. Communication after TBI was described as consisting of more conflict, reduced verbal intimacy (e.g. due to cognitive difficulties) and, according to partners, happening on a different level intellectually and emotionally (Gill *et al.*, 2011). For example:

*'Her comprehension has decreased significantly . . . It's the gist of what I'm saying [that] gets lost frequently. So that's the major source of conflict...'* (p.913; Partner) (Layman, Dijkers & Ashman, 2005).

Some individuals with TBI and their partners were construed as having increased difficulty confiding and sharing with each (Hyatt, Davis & Barroso, 2015), which resulted in miscommunications (Hyatt, Davis & Barroso, 2015), which may account for what was labelled as increased '*guesswork*' (p.62) by both dyad-individuals in Gill *et al.*'s study (2011). Some partners perceived the person with TBI as more defensive in conversation, particularly when discussing TBI-related difficulties (Gill *et al.*, 2011). Positive communication was described when couples adopted some of the following styles: open communication; increased perspective-taking, understanding and empathy; compromise; humour; and open discussions around each others' expectations and needs (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016).

Couples often reported that the changes following TBI exacerbated pre-injury sources of conflict by increasing the magnitude and frequency (Hyatt, Davis & Barroso, 2015; Layman, Dijkers & Ashman, 2005). For people with TBI, this resulted in them deliberately engaging in self-isolation and for partner's feeling as though they are 'walking on eggshells' (p.304; Partner) (Hyatt, Davis & Barroso, 2015). Cognitive

difficulties and non-visible changes in the person with TBI were also often cited as a source of conflict by partners (Hyatt, Davis & Barroso, 2015).

*Changes to sexual relationship.* Although not a primary focus of this synthesis, aspects of couples' sexual relationships were mentioned in nearly all the included studies (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991). Couples reported changes to the frequency (Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005), changes to sexual style and behaviour (Gill *et al.*, 2011), changes to their levels of satisfaction (Layman, Dijkers & Ashman, 2005) and changes to interest and importance placed on sexual intimacy (Gill *et al.*, 2011; Layman, Dijkers & Ashman, 2005). In light of these changes, partners sometimes described increased sexual incompatibility and frustration towards unmet needs (Gill *et al.*, 2011). Changes in interest were reported by both individuals; people with TBI stated being less interested in sexual intimacy due to difficulties with self-confidence and pain (Gill *et al.*, 2011), whereas partners attributed their own reduced interest to increased role strain and stress (Gill *et al.*, 2011). Some partners in Gill *et al.*'s (2011) study questioned if it was morally or ethically right to be sexually intimate with the individuals with TBI. Other partners in this sample also disclosed trying to use strategies to encourage person with TBI's sexual behaviour (e.g. using incentives and rewards), which was received with a mixed reception. Although many couples across studies reported reduction in their sexual intimacy, one couple in Jacobsmeyer Werner's (2016) study disclosed that they had '*found other ways to stay engaged with one another and enjoy each other's company*' (p.105; Researcher).

*Changing perspectives and acceptance.* All studies (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991) depicted couples actively changing their perspectives or their perspectives changing secondary to their experiences. Partners in Willer *et al.*'s (1991) study noted needing to be more aware of their bias in attributing the family's problems to the TBI. Additionally, within this study, some of the people with TBI described difficulties developing realistic appraisals of their own abilities and limitation. Mismatched expectations around abilities were also described within couples in Hyatt, Davis and Barroso's (2015) study, which was associated with increased tension. These findings

were reflected in Gill *et al.*'s (2011) study, where couples described needing to work on understanding each other's needs and feelings more.

Acceptance of changes were described as a '*constantly evolving process*' (p.304) and involved finding a '*personal new normal*' (p.305) for the couple (Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016). A few couples reported not fully accepting the changes with some implying that they did not need to as they believed the person with the injury would continue to make a full recovery (Hyatt, Davis & Barroso, 2015).

### 3.6.3. *Dealing with changes (Coping strategies)*

Both internal and external coping strategies were described to varying degrees across studies (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991). Internal strategies included: greater acceptance of imperfections (Layman, Dijkers & Ashman, 2005); using radical acceptance (Jacobsmeyer Werner, 2016); externalising and compartmentalising the injury (Jacobsmeyer Werner, 2016); change in philosophical stance (Gill *et al.*, 2011) such as '*taking things one [day/step] at a time*' (Hyatt, Davis & Barroso, 2015; Willer *et al.*, 1991); and spirituality (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Willer *et al.*, 1991). In Willer *et al.*'s (1991) study, both the individuals with TBI and their partners explained the need to be more assertive in their relationships (e.g. people with TBI reassuming family roles; and partners dealing with the individual with TBI, professionals and other family members) (Willer *et al.*, 1991). Other coping strategies described by partners included using humour (Gill *et al.*, 2011; Willer *et al.*, 1991) and/or suppression of emotions when reacting to mood swings and personality changes.

Meanwhile external strategies proposed by people with TBI included using memory strategies (Hyatt, Davis & Barroso, 2015; Willer *et al.*, 1991) or enlisting partners support (Willer *et al.*, 1991). In Willer *et al.* (1991), people with TBI also report that being involved in family decisions helped them to feel as though they were fulfilling their original family role. Partners report using proximity seeking strategies to manage ongoing medical issues and safety concerns (e.g. frequent check-ins, safety devices) (Jacobsmeyer Werner, 2016). Partners also highlighted the need to take time to

themselves, which will be explored further under the 'separation' concept. Individuals with TBIs and partners from different studies also conveyed the importance of being involved and engaged in external networks and activities (Hyatt, Davis & Barroso, 2015; Willer *et al.*, 1991).

#### 3.6.4. Other contextual factors

Services. A couple of studies (Jacobsmeier Werner, 2016; Willer *et al.*, 1991) referred to the involvement of services in providing support (e.g. support groups or rehabilitation) for either people with TBI and/or their partners. Support groups for people with TBI were valued by both the individuals with TBI themselves and by some of their partners (Willer *et al.*, 1991). One study reflected on the involvement of services in supporting the couples' relationship dynamics and this was in terms of allowing for more autonomy within the relationship when it was not possible for the person with TBI to be left alone (e.g. when the partner returned to work) (Jacobsmeier Werner, 2016).

*The wider family and system.* References towards the wider family and system were made across all studies (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeier Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991). Families in one study were explicitly identified struggling to accept the TBI changes (Hyatt, Davis & Barroso, 2015). Another suggested that the families' '*unhelpful responses*' acted as a barrier to the couple's intimate relationship. The families' responses were attributed to '*misinformed views of [brain] injury, the resulting disability, or the survivor's behaviour*' (p.63; Researchers) (Gill *et al.*, 2011). These responses sometimes also contributed to partners feeling that they had to assume sole responsibility for the person with TBI and often expressed feelings of isolation (Gill *et al.*, 2011). Couples with children were often cited facing unique challenges. For example, partners expressed concerns around meeting their children's needs whilst acting as caregivers for the people with TBI (Gill *et al.*, 2011; Willer *et al.*, 1991). Another study reported that managing TBI changes resulted in adjustment to the whole family's routine (Hyatt, Davis & Barroso, 2015).

Couples generally described social support as being beneficial (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015), particularly in cases when one of the dyad-individuals perceived that they were no longer able to rely on or getting enough support from their respective partner (Hyatt, Davis & Barroso, 2015). For some, this increased their reliance on their external network (Hyatt, Davis & Barroso, 2015; Layman, Dijkers & Ashman, 2005). External support aided caregiving activities and supporting safety management (e.g. when the person with TBI was at home alone), which was also

described to facilitate marital functioning and autonomy within the relationship (Jacobsmeier Werner, 2016).

*Separation.* Separation was an interesting concept within the studies and was primarily recorded in two studies (Gill *et al.*, 2011; Jacobsmeier Werner, 2016). Physical separation was described within the context of unintentional separations (e.g. as a result of medical procedures or rehabilitation) or intentional separations. Some intentional separations resulted from other commitments competing for the partner's time (e.g. work), or for respite purposes or used in order to gain perspective (e.g. following conflict). Regardless of whether the separations were intentional or not, these evoked feelings of anxiety and isolation within people with TBI, which were expressed as barriers to the intimate relationship and attachment of the couple (Gill *et al.*, 2011; Jacobsmeier Werner, 2016).

*Non-TBI factors.* In four of the five studies (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeier Werner, 2016; Layman, Dijkers & Ashman, 2005), participants described other ways to explain and make sense of the changes (i.e. attributions), as well as other factors that influenced their reactions or ability to cope with the changes. Some of the changes experienced by the couples were attributed to other factors such as age and ageing (Layman, Dijkers & Ashman, 2005). Interestingly, some of the couples where the injuries were sustained during combat, '*accepted the changes in their lives as part of being in the military*' (p.305; researcher) (Hyatt, Davis & Barroso, 2015), which suggests that the context could strongly influence how they make sense of their experiences and changes.

Sometimes, couples' reactions and responses to the TBI appeared to be mediated by factors such as: learning from previous experiences involving adjustment or dealing with difficult circumstances (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Layman, Dijkers & Ashman, 2005). In Hyatt, Davis and Barroso's (2015) military study, they described couples with previous experience of reintegration and home coming '*had learned the "do's and don'ts" from their past reintegration experiences*' (p.304; Researcher), which supported adjustment following the person with TBIs return after their TBIs. Participants in one study also had previous professional experience of disability, which was perceived valuable to the couples coping (Gill *et al.*, 2011):

*'Thank the Lord, I did have some perceptions of what was gonna go on and what was going on because I think [of persons] that have to learn all of that and then still have to deal with all the difficulties'* (p.64; Partner) (Gill *et al.*, 2011)

Lessons from past relationship experiences and attitudes towards separation and divorce also influenced couples in a number of ways, such as: reluctance to go through the separation experience, being conscious that a future relationship may not be better, awareness towards possible financial or social repercussions and personal stance against separation/divorce (Layman, Dijkers & Ashman, 2005). For example:

*'This is my second marriage and I'm 65 already and . . . how many years do I have left . . . I went through a bad divorce.... So I don't want to go through another divorce'* (p.919; Person with TBI) (Layman, Dijkers & Ashman, 2005)

Additional factors included spirituality (Jacobsmeier Werner, 2011) and pre-injury foundation, strength and commitment (Gill *et al.*, 2011). For example, strong pre-injury relationships were thought to act as a buffer the negative effects of TBI changes (Gill *et al.*, 2011).

*Commitment and love.* A few studies described concepts associated with feelings of commitment or love (Gill *et al.*, 2011; Jacobsmeier Werner, 2016; Willer *et al.*, 1991), which was associated with relationship persistence. This included: unconditional, unselfish love, *'vested interest'* (p.914; Researcher) (Layman, Dijkers & Ashman, 2005) and being there for each other or willing to work on and improve their relationship. Some of the other reasons given by couples for their relationship endurance included that philosophy on marriage or as they wanted to set an example for their children (Jacobsmeier Werner, 2016). People with TBI particularly experienced greater appreciation for their partner, which, in return, bolster their partners (Gill *et al.*, 2011).

#### 4. Discussion

This mixed-method synthesis review summarised the current available research evidence-based exploring couples' experiences and relationship quality after a TBI from a dyadic perspective. The emphasis on dyadic research was used to help gain a broader and more holistic understanding of the experiences of the individual with TBI, their partner and the interactional, relational processes between the couple.

This systematic-synthesis review yielded a larger number of dyad studies than those included in the previous narrative reviews that focused on couples relations after TBI (e.g. Blais and Boisvert, 2005; Liss and Willer, 1990; Godwin *et al.*, 2011). A total of eight eligible dyad-relationship studies were identified. Variation between the number of studies included in each review is likely to have been influenced by differences in the review's: main aims or objectives, research questions and/or methodologies. For example, Godwin *et al.*'s (2011) review focused on quantitative studies and only included studies had at least one form of relational measure, whereas the selection criteria within the current review specified that the quantitative studies required a measure of relationship which was also provided for both dyad-individuals. The current review also included qualitative studies and was conducted using a mixed-method synthesis methodology, which significantly deviates from the previous narrative reviews. This is likely to have increased the yield of the number of studies identified through the process of systematically searching several databases. Regardless, the total number of included qualitative and quantitative dyadic studies remained discrete. Due to the limited number and variability between the studies, only provisional conjectures could be made based on the current eligible studies.

The findings from the quantitative studies suggested that couples often express poor relationship quality following TBI with partners reporting significantly more dyadic dissatisfaction and overall poorer relationship adjustment. These findings highlight the importance of recognising the impact of TBI on couples' relationships; however, the limited number of studies and variation between the studies' designs and methodologies remain as significant caveats to the interpretation of the findings. For example, there was no agreed measure for relationship quality (e.g. Dyadic Adjustment Scale; Spanier, 1976; Revised Dyadic Adjustment Scale; Busby, Crane, Larson &



Christiansen, 1995; Index of Marital Satisfaction; Hudson, 1982) and although the majority of measures were expressed as having good psychometric properties and had previously been used within other health-related settings, the current authors have queried the appropriateness of using the measures for a TBI population. For example, the majority of measures were not specifically design for a TBI population and, therefore, may not be sensitive to the types of relationship changes experienced by couples who have experienced a TBI. In addition, the accessibility of the measures for those with TBI are also questioned. For example, the designs of the measures may not take into account the various factors that can influence the person with TBI's ability to accurately report their experiences, such as difficulties with receptive communication or abstract concepts (Paterson & Scott-Findlay, 2002). This emphasizes the importance of researchers paying attention to possible TBI-specific reporting difficulties when considering the used of qualitative measures for assessing relationship quality.

Two of the included studies compared the experiences of the partners to the person with TBI, however it is also acknowledged that the accuracy of making direct comparison between couples' ratings may be influenced by other confounding variables (e.g. social desirability, denial or anosognosia which refers to difficulties with insight resulting from organic causes). Within the TBI population, it has been suggested that denial can have a protective factor for the person with TBI and that '*achieving acceptance [may be] neither realistic nor desired*' (p.1007) (Verhaeghe *et al.*, 2005). Informant-partner responses are often used for triangulation within research to increase the accuracy and objectivity of the person with TBI's self-report, however responses given by partners may not be as objective as generally presumed in the literature (McKinlay & Brooks, 1984). McKinlay and Brooks (1984) acknowledged that the informant's personal characteristics and active adjustment and coping processes (e.g. level of distress) may also impact of their reporting style.

Analysis of the qualitative studies found that experiences and responses from the people with TBIs, their partners and collectively as couples produced comparable and contrasting accounts. Variations among their accounts influenced their relationship dynamics and how they coped. The findings also drew attention to other contextual factors that influenced couples' attributions and perceptions toward the TBI-related changes. The analysis highlighted the individual experiences of people with TBI and

their partners, as well as the possible reciprocal interplay between the couples' experiences. Interestingly, the content of accounts given by people with TBI sometimes mirrored those provided by their partners, which implied that, to a degree, they were able to recognise not only the impact and consequences of the TBI for themselves, but also their partners. On one level this may challenge previous misconceptions that difficulties with insight and aspects of cognitive functioning (e.g. memory) limit the ability of people with TBI to participate fully in the interview process (Paterson & Scott-Findlay, 2002). However, this may also be the result of biases created by the samples or the sampling recruitment procedures (e.g. self-selection). For example, those with more insight may be more willing to participate in studies of this nature or it may be possible that, at the time of recruitment, couples where the person with the TBI had greater insight were more likely to have remained together and, therefore, meet inclusion criteria for the studies (e.g. no changes in relationship status); however further research would be required to explore these potential confounding factors.

The qualitative synthesis found that the physical, cognitive, emotional and behavioural consequences of TBI influenced the people with TBI and their partner in a variety of ways, which also influenced how they approached and interacted with each other and within their relationships. For example, the loss of autonomy and increased reliance on their partners resulted in reduced confidence for people with TBI, whereas changes in physical functioning resulted in difficulties in their expression of affection and intimacy. Changes in emotion management and increased difficulties with anger and aggression were cited as problems by partners and people with TBI. These often were expressed as having a direct impact on partners, where partner sometimes described feeling 'unprepared' for these changes.

Changes in couples' relationship dynamics included: changes in roles, increased dependence, changes in communication and their sexual relationships. Changes in roles and communication were most likely to be cited across all studies. Changes in roles were acknowledged for both individuals and included increased pressure on partners to adopt a 'caregiver'-type role and people with TBI often experienced loss of their previous roles. These were seen to disrupt the equilibrium and traditional structure of couples' dynamics. Meanwhile, quality of communication post-injury was described as mixed. Some couples reported reduced conflict due to changes in perspectives (e.g.

no longer feeling the need to be 'right'), whereas other suggested increased conflict and misunderstandings due to increased guesswork by both individuals. The changes in couples' dynamics highlight the importance of recognising the interconnectedness and interplay between the person with TBI, their partner and their relationship (Gill *et al.*, 2011).

There has been no consensus among researchers in support of any single theory or model to fully account for all aspects of couples' experiences post-injury (e.g. stress-coping theory, models of adjustment, family systems perspective, marriage and family therapy model) (Liss & Willer, 1990; Moore, Stambrook & Gill, 1992; Verhaeghe *et al.*, 2005). Verhaeghe *et al.* (2005) suggested systems theory may help increase understanding towards the complex interplay between the individuals and their partnership. This theory suggests that change to one part of the system (e.g. a TBI) results in changes for the individual with TBI and their partner. Furthermore, the way each person copes and respond with have an interactional effect on the other person in the relationship and vice versa. Although a useful theory for increasing emphasis on systemic factors and the interacting relational dynamics, it may not fully account for the separate intrapersonal changes experienced by each dyad-individual.

#### *4.1. Strengths and weakness of the review*

Although deemed more objective than traditional narrative reviews, the level of objectivity that can be feasibly achieved through systematic and synthesis reviews remains debated (Sandelowski, 2008). Researchers (e.g. Sandelowski, 2008) continue to report possible areas of bias and subjectivity in the review's initial development (e.g. defining the research questions), design and methodology (e.g. variations in conducting the search), analysis of the studies (e.g. method of data analysis) and interpretation and presentation of the findings, which are also open to the perspectives and preferences of the authors. A review is suggested to be systematic when it adheres to a protocol (Sandelowski, 2008), which the current review aimed to do. Typically, systematic reviews are defined by their systematic procedure, which increases their procedural replicability and reliability. This can be problematic when also including qualitative research, particularly during the database searches as qualitative studies can be more difficult to identify due to poor indexing for example

(Petticrew & Roberts, 2006). Some steps were taken to increase the yield of possible eligible studies during the computerised systematic database search whilst adhering to a systematic procedure; for example, differentiation between eligible qualitative and quantitative was conducted during the screening stage as opposed to the identification stage. This meant the search terms were not defined by their specific research design (i.e. qualitative or quantitative) and allowed for the search terms to be kept broad. A search of the grey literature was also included, which also reduced the likelihood of publication bias.

The use of interrater reliability during different stages of the systematic review was viewed a strength and enhanced consistency in the application and interpretation of the: selection criteria during the screening and eligibility stage, and of the quality rating tools during the quality review. Moreover, the agreement between researchers was encouraging and found a moderate agreement in the selection criteria and moderate to substantially high for the quality rating tools. Due to variations in study design, more than one quality assessment tool had to be applied. Among the tools included AXIS (Downes *et al.*, 2016), which is relatively new and, therefore, is not as well-established as other quality appraisal tools; however, the number of available tools developed for cross-sectional studies remains limited (Downes *et al.*, 2016).

Metaethnography was used to synthesize the qualitative studies. As previously mentioned, this approach has been used in a number of healthcare synthesis reviews and is sometimes preferred over other types of qualitative synthesis due to its degree of transparency and as it allows for the final synthesis to be strongly based within the original studies' findings (Noblit & Hare, 1988). The current authors, however, are mindful to the fact the application of metaethnography continues to evolve and the method remains open to criticism due to the variations in the procedure, which can limit its application in a standardised way (Campbell *et al.*, 2012).

As highlighted by the JBI-QARI quality assessment, none of the included studies in the metaethnography had adequately and explicitly reflected on influence of the researcher on the research (e.g. researcher's stance and characteristics), and vice versa. This proved challenging to determining the accuracy of the included studies researchers' interpretations and representations of their participants' voices (i.e. second-order

interpretations), which is acknowledged here as this may have had an impact on the synthesis of the included studies' findings (i.e. third-order interpretations).

One of the strengths of the current reviews was that, to date, this is the only systematic review that has attempted to explore couples' experiences and relationships from a dyadic perspective. This is in spite of the reviews difficulties to make any clear conclusions as it was limited by the small state of the current evidence-based and heterogeneity between studies.

## 5. Conclusion

The number and types of implications and recommendations that can be derived based on this review are restricted and caution is encouraged in the interpretation of these due to the limited current state of the evidence-based and also the review limitations.

### 5.1. *Implications for practice*

One of this review finding's main implications for healthcare professionals stems from the basis that TBI does not happen in isolation. This encourages healthcare professionals to consider the wider interactional and systemic influences. This also raises issues around where, when and how to best address the different difficulties experienced by the system, whilst acknowledging the possible changes over time (e.g. considering the recovery journey and fluctuations in coping processes between individuals). In addition, increased recognition and awareness from healthcare professionals towards the experiences of couples would be beneficial generally (Moore *et al.*, 1992). The more systemic approach challenges the traditional individualistic configuration of services and poses problems for services that are already struggling and under significant pressure to meet the needs of the people with TBI, let alone the needs of their partners and couples as a whole.

### 5.2. *Implications for research*

Unsurprisingly, further dyadic, TBI-specific research is strongly recommended both quantitatively and qualitatively. The research should differentiate between TBI and other acquired brain injury experiences and also differentiate between the various family member experiences. Further research exploring couples' experiences and relationships would likely benefit from larger and multi-centred sampling (Godwin *et al.*, 2011) in order to increase sample representativeness to the target population. This would also allow for further exploration of the extent to which different demographic factors (e.g. age, gender), brain injury characteristics (e.g. level of severity) or recovery-based experiences (e.g. time) influenced the couples' experiences. Researchers are encouraged to be mindful towards possible biases created through self-selection recruitment, recruitment through clinical populations and issues with non-

responders. Understanding of couples' experiences and relationships would be greatly enhanced through conducting more longitudinal studies (Perlesz *et al.*, 1999). This may help to clarify the constantly evolving picture for couples post-injury and could potentially provide insights into possible factors that influence couples' relationship instability.

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### **Conflicts of interest**

The authors declare no conflict of interest with respect to this paper.

### **Declaration of Interest**

n/a

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## **Chapter 2:**

### **EMPIRICAL QUALITATIVE STUDY**

#### **Couples' experiences and relationships after traumatic brain injury**

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## **Abstract**

**BACKGROUND:** Traumatic brain injuries (TBI) can directly affect the person who has sustained the injury, as well as sometimes having profound consequences for those around them.

**OBJECTIVE:** To qualitatively explore the impact of TBI on couples' experiences and relationships.

**METHODS:** Independent interviews were conducted between the five individuals with TBI and their partners. Participants included: couples where the person with TBI had returned to the same co-habiting, pre-injury relationship; and had returned home for a minimum of one to five years since discharge from inpatient care or rehabilitation. The interviews used an a priori semi-structured approach and explored topics around: communication, role changes, commitment and intimacy, shared activities and treatment and support. The data collected was analysed using a combined deductive-inductive Framework Analysis approach, which supported comparisons between and within couples.

**RESULTS:** Deductive and inductive analysis of the interviews identified three overarching themes: 'You begin to realise that, actually, life may not be the same ever [again]...' (Partner); Perceived influences of and influences on relationships endurance following TBI and Contextual and other factors. These explored the impact of TBI on couples' relationships and processes that interacted with or influenced their relationships endurance.

**CONCLUSIONS:** Increased dyad awareness is encouraged within research and healthcare practice due to the complex interplay between the individual with TBI, their partner and within the couples' relationship following TBI.

**Keywords:** Traumatic brain injury (TBI), couples, relationships, qualitative research, framework analysis

## 1. Introduction

Researchers within the field of traumatic brain injury (TBI) are showing increased interest in the impact and disruption of TBI to the person with TBI's family system (Godwin, Kreutzer, Arango-Lasprilla & Lehan, 2011). Family involvement can be vital to the person's recovery and rehabilitation (Mauss-Clum & Ryan, 1981; Verhaeghe, Defloor & Grypdonck, 2005) and significant disruption to the system can have long-term consequences for both the family and the person with TBI (SIGN 130, 2013).

The type of disruption that TBI can cause may vary depending on the family member, their role and the type of relationship with the person with TBI (e.g. parent-child, partner-partner). Where studies have differentiated between the family members' experiences, the majority have focused on making comparisons between parents and partners. These comparison studies have produced a mixed picture around levels of carer burden, stress and distress. Some studies have suggested no significant differences when using measures of stress or distress (e.g. Allen, Linn, Gutierrez & Willer, 1994; Anderson *et al.*, 2009; Brooks, Campsie, Symington, Beattie & McKinlay, 1987; Livingstone & Brooks, 1985), whereas others have suggested that partners may experience greater stress and/or distress than parents (e.g. Gervasio & Kreutzer, 1997; Panting & Merry, 1972). Consensus has been found in the study of the qualitative differences in the nature and types of experiences between parents and partners. For example, differences in interactional or relational patterns and types of challenges experienced by parents compared with partners (Brooks *et al.*, 1987; Anderson *et al.*, 2009). Parents have been described returning to their previous parental and caregiver roles (Gervasio & Kreutzer, 1997; Serio, Kreutzer & Gervasio, 1995; Wood, Liossi & Wood, 2005). Although authors report that parents can experience higher levels of frustration and have more concerns (with less realistic expectations) associated with the person with TBI's long-term progression (Allen *et al.*, 1994), the partners' experiences continues to be described as more difficult and stressful (e.g. Liss & Willer 1990; Perlesz, Kinsella & Crowe, 1999). Partners are reported to experience loss of their peer-based, reciprocal partnership, as well as loss of their source of companionship and emotional support (e.g. '*I have lost my best friend*'; Wood, 2006; p.139) (Lezak, 1988; Gervasio & Kreutzer, 1997). Partners may also experience increased financial strain (Gervasio & Kreutzer, 1997) and loss of mutual parenting

support in families with young children (Blais & Boisvert, 2006; Perlesz *et al.*, 1999). Several authors (e.g. Lezak, 1988; Perlesz *et al.*, 1999) have also described the ‘social limbo’ (Wood, Liossi & Wood, 2005) and ‘disenfranchised grief’ (Doka, 2014) that partners can experience. These terms have been used to explain the lack of sanctions for partners to formally grieve and mourn the losses resulting from TBI (e.g. roles, status, etc) (Lezak, 1988).

Relationship instability and divorce has been widely documented within the literature. Wood and Yurdakul’s (1997) study found that only 42% of 131 couples with mild to very severe TBIs were able to maintain their relationships longer than five years, with marital separation being more common than divorce. Other studies have estimated relationship instability ranging from 15% to 54% (Anderson-Parente, DeCasare & Parente, 1990; Kreutzer, Marwitz, Hsu, Williams & Riddick, 2007; Kreutzer, Sima, Marwitz & Lukow., 2016), with more recent studies proposing that prevalence rates may not be as high as previously suggested. One reason for the inconsistencies may be due to methodological variations, such as differences in the lengths of time since injury in the samples for different studies. This may be important as relationship instability has been suggested to increase with time as couples experience greater relationship dissatisfaction (Wood & Yurdakul, 1997). On the other hand, some authors (Lezak 1988; Wood 2006) have proposed that the ‘moral dilemma’ couples face may explain the increased rates of couples remaining in unhappy relationships. The ‘moral dilemma’ has been described as the couples’ reluctance to engage in divorce or relationship dissolution due to feelings of responsibility, guilt, fear and/or social condemnation.

Difficulties with ‘moral dilemma’ and variable rates of relationship instability places the emphasis on researchers to gain a better understanding of the quality of couples’ relationships and their experiences post-injury. Although researchers over the last few decades have called for this type of research (e.g. Blais & Boisvert, 2005; Godwin, Kreutzer, Arango-Lasprilla & Lehan, 2011; Liss & Willer, 1990), the evidence-based remains within its infancy. In part, this has been exacerbated by the lack of consensus between researchers around their primary objectives (i.e. focus on couples’ experiences or relationship quality) and how best to define and measure the key variables. For these reasons, findings from quantitative studies have resulted in a



multitude of proposed variables influencing couples' experiences and relationship quality following TBI (e.g. financial difficulties, injury severity, injury-related consequences, presence of children, available support for partners, coping strategies, and insight) (see Perlesz *et al.*, 1999; and Blais & Boisvert, 2006). Qualitative research may provide added richness to this area by increasing understanding towards the lived experiences of the couples, which may also help to narrow the focus for future research. Although the value of qualitative research continues to grow and be recognised by researchers and clinical practitioners, qualitative exploration within this area remains scarce (see Blais & Boisvert, 2005; Godwin *et al.*, 2011; Liss & Willer, 1990). Moreover, the majority of the qualitative studies have relied on one perspective (i.e. either the person with TBI or the partner) to gain an understanding of the couple's experiences (Godwin *et al.*, 2011; Blais & Boisvert, 2005). This has acted as a barrier to gaining a holistic understanding of couples' experiences and their relationships. This also ignores any potential shared or interactional processes between the dyad-individuals. There have only been a handful of dyadic qualitative studies that have focused on couples' experiences post-TBI (e.g. Gill, Sander, Robins, Mazzei & Struchen, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer, Allen, Liss & Zicht, 1991). Some examples of the types of changes in the couples' experiences across the studies, included changes in roles (Gill, Sander, Robins, Mazzei & Struchen, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991), communication styles (Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005) and sexual intimacy (Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer, Allen, Liss, Zitch, 1991). It is important to recognise that the methodological designs (e.g. grounded theory, IPA, content analysis) and sample populations (e.g. participant genders, sexual orientations, etc) varied across studies. In addition, the majority of the studies had a general focus on couples' experiences with very few explicitly emphasizing the couple's relationship itself (e.g. Gill *et al.*, 2011; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005). Furthermore, all of the studies were conducted outside of the UK.

### 1.1. *Aim*

Using a dyadic framework, the current study aimed to qualitatively explore the impact of TBI on couples' experiences and relationships using a UK-based sample. For the purpose of this study, the term 'relationship' refers to the couples' intimate and interpersonal relationship. This was defined as how couples emotionally and cognitively relate and interact with one another and was adapted and abbreviated from Gill *et al.*'s (2011) study.

## **2. Methods**

Although the use of reporting checklists within qualitative research is debated (see Barbour, 2001), this study consulted the Consolidated criteria for reporting qualitative research checklist (COREQ; Tong, Sainsbury & Craig, 2007) to help increase the reporting transparency.

### *2.1. Design*

The study received ethical approval from the North of Scotland Ethics Committee (See [Appendix 4](#)).

A qualitative methodology, inclusive of semi-structured interviews, was employed to gain a detailed understanding of couples' experiences and relationships following TBI. This allowed for further exploration of the topic to a level and depth that may not be easily or feasibly captured through quantitative means.

Framework analysis was employed as the method of data analysis (Ritchie and Lewis, 2003). Framework analysis fits within the subtle realism paradigm (Snape & Spencer 2003), which was in keeping with the researcher's own philosophical stance and suggests that there is an existing reality (as opposed to a 'truth') that can be accessed on some level through the appropriate qualitative means (Hammersley & Atkinson 1995). Unlike other forms of qualitative methodology that have sometimes been criticised for their lack of transparency (e.g. thematic analysis) (Ward, Furber, Tierney & Swallow, 2013), the framework analysis approach has been described as being more explicit, systematic and transparent, and allows for the analyses and interpretation to remain firmly within the original data (Ritchie & Lewis, 2003). One of the added benefits of framework analysis for this project resulted from the ability to take this transparent approach to exploring the data from a theme-based and case-based perspective. This supported the process of exploring themes both between and within dyad-couples (i.e. people with TBI, partners or possible interactional processes) (e.g. Eisikovits and Koren, 2010; White & Newman, 2016).

## 2.2. Participants/Sample

Potential participants included adult, heterosexual couples where the male partner of the dyad has a diagnosis of TBI. The individual with TBI must have returned home to the same pre-injury cohabiting relationship and would have been based at home for a minimum of one to five years before participating in the interview (e.g. following discharge from inpatient care or rehabilitation). All potential participants had to be able to provide informed consent and understand and communicate in English to a satisfactory level for participation in an interview. The inclusion criteria were chosen to encourage data saturation given the time-limited study, as well as to ensure the contributions from potential participants to aid the richness of the data collected to answer the research question(s) (i.e. purposive sampling) (Ritchie and Lewis, 2003; Tong *et al.*, 2007).

Suitable potential participants were recruited either: (1) via poster and self-referral at a local support group (See [Appendix 5](#)), or (2) identified by a clinical neuropsychologist, who had access to a detailed overview of the inclusion and exclusion criteria (see Consultant referrer information sheet in [Appendix 7](#)). The clinical staff were based at one site in Scotland and used a clinical database to identify potential participants. Those who were identified by a clinician as suitable were sent an invitation letter, information about the study and brief relationships (based on the inclusion criteria) screening questionnaire to determine participant suitability for the study (See [Appendix 8](#), [Appendix 6](#) and [Appendix 10](#)). Only potential participants who opted into the study were contacted by the researcher to discuss the study further. Twenty-three participant couples were identified by the clinical neuropsychologists to participate in the study. A total of six couples opted into the study via either clinical identification or poster self-referral. None were excluded and all six initially consented to proceed to interview. Unfortunately, one couple was unable to make the interview due to other competing demands. The final included sample size consisted of five couples. Sample sizes in previous qualitative, TBI and couple-dyad studies varied from three to 47 couples (e.g. Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991), however none of the previously mentioned studies utilised framework analysis. This sample size mirrored other framework analysis studies conducted in different healthcare settings

that were of a similar nature (e.g. Akesson, Worth & Sheikh, 2007; Cup *et al.*, 2011; Patel & Agbenyega, 2013; White & Newman, 2015).

### 2.3. Interview and data generation

Written informed consent was gained from each participant ([Appendix 9](#) example of blank consent form). Participants also completed brief demographic questionnaires ([Appendix 10](#)). The first author facilitated separate face-to-face interviews with people with TBIs and their partners at a local clinical or rehabilitation facility. Where possible, the interviews for both individuals were conducted on the same day (mean=6 days). Independent individual interviews were deemed preferable as this encouraged full expression of experience for each individual and helped to preserve confidentiality between the couple members (Gill *et al.*, 2011). The interview structure and schedule were designed in line with recommendations around methodological adaptations for people with TBI (e.g. Greenwood, Theadom, Kersten & McPherson, 2015; McKinlay & Brooks, 1984; Paterson & Scott-Findlay, 2002) ([Appendix 12](#)). The lengths of interviews ranged from 30 minutes to one hour 12 minutes (mean length of interview=57 minutes). The a priori semi-structured interview schedule (Summary of content areas that guided the interviews is provided in [Table 1](#); full interview schedule is provided in [Appendix 12](#)) was adapted from Gill *et al.* (2011) and White and Newman (2016), which focused on couples' experiences of TBI and the impact on their relationship.

All participants were debriefed at the end of each interview (see [Appendix 11](#) for debrief form). The interviews were audio-recorded, and field notes and reflections were kept from each interview by the first author.

**Table 1. The content areas that guided the interviews.**

Content areas
<i>Definition of relationship</i>
<i>Communication</i>
<i>Role changes</i>
<i>Commitment and intimacy</i>
<i>Shared activities</i>
<i>Treatment and support</i>

## 2.4. Data processing/analyses

**Figure 1. Ritchie and Spencer (1994) and Ritchie and Lewis' (2003) stages of framework analysis**

Five stages of framework analysis:

1. *Familiarization*
2. *Identification of an initial thematic framework*
3. *Indexing and pilot charting*
4. *Charting*
5. *Mapping and interpretation*

The interviews were transcribed and transcripts anonymised. Data analysis followed Ritchie *et al.*'s (i.e. & Spencer; 1994; & Lewis, 2003) framework analysis five stages, as well as consulting worked examples of framework analysis within other healthcare research (e.g. Gale, Heath, Cameron, Rashid & Redwood, 2013; Ward *et al.*, 2013; Parkinson *et al.*, 2016). See [Figure 1](#) for an overview of the stages.

The first few steps were conducted jointly between the first and second researcher (NC and MW). The second researcher, with several years practice in clinical neuropsychology, brought clinical expertise to the analysis. The first author became familiarised with the whole data set (e.g. through repeatedly reading and reflecting on the transcripts and audio recordings) and started to explore the data for initial concepts and recurring themes. A draft framework was developed using a combined a prior deductive and inductive approach, similar to Gale *et al.* (2013) and Parkinson *et al.* (2016). This approach aimed to allow the data to be organised in a meaningful and manageable way that was rooted in the key areas of interests (i.e. pre-defined by previous relevant research and the interview schedule), whilst allowing for themes to emerge through open coding of the data. This draft framework was piloted and applied back to a randomly selected transcript using NVivo 11 software. The draft framework was discussed with the second author who had also familiarised herself with the same transcript. The authors discussed and agreed adaptations to the draft framework ([Appendix 13](#)), which was then systematically applied back to the remaining transcripts by the first author (see [Appendix 14](#) for indexing coding sample). Any further adjustments to the framework were discussed with the second author. The process of indexing and applying the framework back to the transcripts involved rearranging the original transcript data into charts based on their thematic references,

which allowed for transparent and easy theme- and case-based comparisons. Charted summaries were provided for the original charted data using NVivo 11 software, which promoted the final synthesis and interpretation of the data to remain firmly within the original transcript context. It is important to note that there is conceptual overlap between themes and subthemes due to the challenge of organising and/or categorising feelings and experiences that interact or are not mutually exclusive (e.g. feelings of appreciation and the perceived relationship strength) (see Parkinson *et al.*, 2016). The mapping stage, therefore, sat more firmly within the reported experiences given by the couples and resulted in the final themes and subthemes (similar to Midgely *et al.*, 2015). Themes and subthemes represent the ‘keyness’ or importance of the theme to the research question and may not have been expressed in every participant’s interview (similar to thematic analysis approach as described by Braun & Clark, 2006). See [Table 3](#).

## 2.5. *Rigour*

Clinical expert and service user involvement were also used in addition to the previously mentioned strategies to increase qualitative rigour (e.g. multiple coding in the data analysis and keeping field and reflective notes) (see Mays & Pope, 2000). A neuropsychology department was involved during the initial conceptualisation and design of the study. Service users with TBI and one partner from a local support group were also asked to consult on the procedure and participant materials during the initial development. The service user involvement followed recommendations by Trivedi and Wykes (2002) and INVOLVE (Tarpey & Bite, 2014).

### 2.5.1. *Reflexivity*

All of the interviews were conducted by the first author, a trainee clinical psychologist who had previous knowledge and experience of working with the acquire brain injury (ABI) population. All potential participants were primed to the intended area of study (i.e. couples’ experiences and relationships following TBI) via the participant information sheets and through brief discussion with researcher after the potential participants had initially opted-in. Participants did not have any further formal contact with the researcher until the interview.

### 3. Results

#### 3.1. Demographics

Five couples participated in the study. All of whom were White British. The marital status for couples varied: three were reported as married and two were reported as co-habiting. The mean length of relationship was 19 years (SD=11.33; range: 5-30 years). Two couples reported having at least one child aged 18 years old or younger. The couples' educational levels ranged from O-level to university degree level. Two participants with TBI and four partners reported that they were employed at the time of the interview and one person with TBI reported having to retire as a consequence of his TBI. The average time since injury for the couples was 3.15 years (SD=15.27; range=2-5 years). One person with TBI had sustained a mild TBI and four had sustained moderate to severe TBIs. The average age for participants with TBI was 54.4 years (SD=12.44; range=36-66) and 49.8 years (SD=8.58; range=36-57) for partners. See [Table 2](#) for dyad specific demographics. To maintain anonymity, participants with TBI are identified as 'T', partner participants are identified as 'P' and couples are identified as 'C'. The numeric coding for participants were randomly allocated per individual (e.g. 'T1').

**Table 2.** Dyad characteristics

Dyad	Mean couple age (years)	TBI severity	Length of relationship (at time of interview)		
			0-5 years	6-10 years	11+ years
C1	36.0	severe	x		
C2	61.5	moderate			x
C3	57.5	severe		x	
C4	54.5	mild			x
C5	51.0	severe			x



**Table 3. Overview of charted key themes and subthemes (based on Ritchie & Spencer, 1994; Ritchie & Lewis, 2003)**

	T1	T2	T3	T4	T5	Pa	Pb	Pc	Pd	Pe
Interview processes	x		x	x	x	x		x		
<b><i>'You begin to realise that, actually, life may not be the same ever [again]...' (P)</i></b>										
<i>Changes resulting from TBI symptoms on the couple</i>	x	xx	xx	xx	xx	x	x	xx	xx	xx
Effect of time and TBI recovery on the relationship	x	x	xx	xx	xx	xx	xx	xx	x	xx
<i>Changes within the couples' relationship Dynamics</i>										
Communication	x	xx	xx	xx	x	xx	x	xx	x	xx
Role change		xx	x	x		x	x	x	x	xx
Reciprocal support	x	x	x			x		x		
Affection and sexual functioning		x	x	x					x	x
Time together	x	x	x	x	x	x	x	x	x	x
<b>Perceived influences of and influences on relationship endurance following TBI</b>										
<i>Pre-injury factors</i>										
Strong pre-injury relationships	x			x		x		x	x	
Learning from the past	x	x		x	x		xx	x	x	
Having faith					x		xx			
<i>Within relationship post-injury processes</i>										
Relationship strength post-injury	xx	x	x	x	x		x	x		x
Feelings of being understood and	x	x			x	x	x	x	x	

	T1	T2	T3	T4	T5	Pa	Pb	Pc	Pd	Pe
empathy										
Appreciating their partners and partners' support and understanding	xx	x	x		x			x		
Strengthening partnership, shared problems and experiences	xx	x	x		x	x	x		x	x
<b>Contextual and other factors</b>										
<i>Contextual factors</i>										
Family and social system	x	x		x		x		x	x	
Services	x	x	x	x		x		x	x	x
Non-TBI attributions	x	xx	x	x	x	x	x	x	x	x

x Denotes instances of theme or subtheme found in indexing of transcript

xx Denotes themes and subthemes (e.g. the experience of symptoms) highly prevalent as indicated by ten or more instances at a single coded-level per transcript (e.g. The impact and experiences of symptoms: cognitive symptoms).

### 3.2. Overview of themes

When opting-in to the study and during the interview, many of participants implied that their willingness to participate in the study was *'because the injury affect[ed] the couple and not just the person who suffered the injury'* (T) and, therefore felt it was important topic to them.

Three main themes were identified from the interviews using a combined deductive-inductive framework analysis approach: *'You begin to realise that, actually, life may not be the same ever [again]...'* (P); Perceived influences of and influences on relationship endurance following TBI; and Contextual and other factors. These were explored for commonalities and overlap within and between people with TBI, their partners and couples. See [Table 3](#) for an overview of charted key themes.

#### 3.2.1. *'You begin to realise that, actually, life may not be the same ever [again]...'* (P)

When directly asked about the consequence of TBI on their relationships, all of the couples spoke about feeling that their relationships had changed or were different following the TBI. They spoke about the impact of physical, cognitive, emotional and behavioural symptoms on their relationships. Some symptoms were described as having a direct impact on the couple's relationship (particularly emotional and behavioural symptoms), whereas others were described to influence the way the couples interacted and related with each other (i.e. relationship dynamics).

##### 3.2.1.1. Emotional and behavioural TBI symptoms on the couples' relationships

Examples of emotional and behavioural difficulties included increased: anxiety; pessimism and low mood; irritability and anger; rumination, which was sometimes exacerbated by reduced cognitive mental flexibility; and emotional detachment or numbness. Although not problematic before the injury, one partner stated she thought the person with TBI appeared less emotionally reactive (*'He doesn't get as stressed and go off on one about some ridiculous thing that he would blow up before'* P). She also reflected that it helped *'both of [them]'* that he was *'calmer'* (P). In contrast, the majority of couples described negative consequences for partners resulting from

problems with anger and aggression following TBI (e.g. *'I'd lose my temper over the tiniest things and [partner] took the brunt of this'* T). This was acknowledged by partners and the people with TBI alike. Increased anger and aggression sometimes influenced how close the couples felt (e.g. *'Well when you've got a lot of arguments and aggression and fall out's you don't feel so close to that person'* P) and also resulted in some partners feeling isolated or lonely within their relationship (e.g. *'at times, feel extremely lonely because... [pause] if [partner] is tired and has just been... awful, which he can be at times'* P).

#### *The effect of time since injury and TBI recovery on the relationship*

Acknowledgements to improvements or changes in the person with TBI's presentation as time progressed inductively emerged from couples' interviews. Couples noted, however, that the recovery journey was not as clear or predictable than they had first expected or, in part, hoped:

*'I think in my recovery... I had hoped to carry on my recovery in a straight line, keep getting better and better. But it wasn't. I wasn't prepared that it could be a wavy line as I was told'* (T)

*'It's been hard to get back. I would like... sometimes I feel I'm almost there and I slip back a bit'* (T)

Nearly half of the participants expressed a sense of certain symptoms lingering or that the person with TBI's recovery was *'dragging on'* (P), which was a source of frustration for both partners and people with TBI. Changes in partners' abilities to remain patient and expression of frustration were noted as time progressed by two partners and a person with TBI. One partner explained the change as: *'Umm... at that time I don't think it did so much because you are in the coping and you just get on and that's just what you do. I think that it's actually when you start on the road to recovery, you start allowing yourself to be irritated by things as opposed to concerned. That you switch from worrying about things to just either being irritated or wishing it would be different. Umm... Resentful, I don't know if I would go as far as resentful... But irritated...'* (P). Feelings of frustration were associated in reductions in the couples' feelings of closeness and intimacy, which are explored further under the subtheme of Affection and sexual intimacy.

### 3.2.1.2. Changes within the couples' relationship dynamics

Relationship dynamics refer to the way in which couples' interacted with and related to one another. Changes resulting from TBI were primarily developed deductively and included changes in aspects of the couples' communication, roles, time spent together and affection and sexual intimacy.

#### *Communication*

Changes in communication were expressed by all participants and ranged from changes due to TBI symptoms or changes in couples' quality and style of communication.

*Communication changes due to TBI symptoms.* This subtheme was primarily inferred from the partners' accounts where they described changes in communication resulting from the person with TBI's cognitive functioning. These ranged from the person with TBI needing additional time to process information, to difficulties with memory, to changes in the ability of the person with TBI to self-monitor or manage their tone of voice. Difficulties with memory lead to feelings of frustration in both the person with TBI (e.g. due to difficulty learning and retaining information relayed by their partner) and partners (e.g. due to having to repeatedly remind the person with TBI of previous conversations). For example: *'She doesn't nearly tell me as much as she could. Probably to stop me from saying, "I've forgotten... forgotten you told me that"'* (T). It was reflected by one partner that this sometimes triggered beliefs that the person with TBI was not listening to her, however she also associated this with the person with TBI's ongoing difficulties with physical discomfort or pain.

A few partners also recognised changes in the person with TBI's level of understanding. This included struggling to understand more complex or abstract concepts, such as sarcasm or humour (*'You know we [sigh] the humour is coming back not because he lost it, but his sense of humour changed, he did not understand. I mean I... sarcasm is my second language so... Sarcasm doesn't work if you're thinking literally'* P). Sometimes, changes in the person with TBI's receptive understanding

affected the way partners communicated with them. This included simplifying language, being more direct (i.e. '*telling him*' P) or '*nagging*' (P) in conversations. This felt uncomfortable for some partners. One partner also reflected that in her attempts to make information less complex, she felt '*a lot of nuances*' in their conversations and relationship would be lost. Although most of the individuals with TBI were unable to identify specific changes in their partners' communication style when asked directly, one person stated that he felt his partner spoke to him like a '*child*' (T), which he described felt 'terrible' and did not think his partner realised the impact on him.

*Quality and style of communication.* Changes in the quality and style of communication were expressed by all couples, both people with TBI and partners. Some spoke about being more open with one another. For example, a few partners mentioned increased emotional openness and emotional investment by the person with TBI, which they felt benefitted their relationships (e.g. reducing guesswork: '*He's definitely more open... talking about his feelings than he ever was. I think before umm... I would never quite know what was on his mind*' P). A couple of partners also reflected that they had to be more open with each other as a result of the TBI, such as discussing the couples' feelings of commitment to each other or around the couples' day-to-day activities and plans.

On the other hand, other couples stated that they felt they communicated less with each other or the partners were more likely to hold information back from the person with TBI. For people with TBI, this sometimes evoked feelings of frustration, sadness, isolation or anxiety (e.g. increasing guesswork: '"*What is wrong? There must be something wrong*"' T). The reasons for the changes varied. Partners spoke about not '*bother[ing the person with TBI] with trivial, trivialities of the day*' (P) or trying to protect the person with TBI (e.g. '*So, I didn't want to make that something worse*'). Both partners and people with TBI recognised the partners' concerns around how people with TBIs may react and, therefore, partners were less likely to share as much (e.g. '*She, there is a few things that she won't or doesn't, no she won't, she doesn't, eh, umm, include me in and speak to me about I suppose because she is worried about how I will react*' T). Although reducing with time, one partner felt that the person with TBI was less likely to share with her his actual thoughts and was more likely to give her socially desirable responses:

*'There are times where we would have a conversation and I'm thinking that's absolutely how our conversation would have gone before. And other times in conversation I would see him... saw him... not so much now... but saw him struggling to... I don't think it was just to express what he wanted to say but express what was the "right" thing to say and he would be struggling to find [it]...'* (P)

### *Role change*

Role changes were depicted by nearly all of the couples and were noted to change over time and with the individual's recovery. Role changes referred to changes in '*participation in partnership activities*' (p.915; Layman, Dijkers & Ashman, 2005) and were associated with increased reliance and dependency due to the person with TBI's changes in physical, cognitive and emotional functioning.

*Increased reliance and dependence - 'the give and take was very equal, whereas now I feel that it's more... I take a lot more than I give'* (T). Changes in cognitive (e.g. memory difficulties, changes in executive functioning and disinhibition) and physical functioning (such as fatigue, pain and functional ability) were reported to increase reliance on partners for emotional support or reassurance and/or practical support. Due to reduced changes in confidence and ability, people with TBI often sought more reassurance and emotional support from partners around planning and organising tasks. With regards to practical support, partner took on roles to support the person with TBI to liaise with professionals, monitor medication, driving, monitor written communication and research information about TBI. People with TBI's inability to drive was expressed by many partners as increasing pressure on them, particularly to support the person with TBI to get to and from destinations.

*Balance of roles.* Changes in ability of the person with TBI and increased reliance on partners disrupted the equilibrium and balance of roles within relationships (e.g. '*I wouldn't go as far as role reversal...*' T). This influenced the balance and division of responsibilities and tasks taken by the couple (e.g. at home: housekeeping, cooking and managing finances), particularly for partners. This resulted in the loss of their equal partner-role, change to previous roles (e.g. '*bread winner*') or adoption of new roles. For example, partners indicated assuming new roles as gatekeeper,

*'therapist' (P) or 'expert' (P). For many partners, these changes to the roles had to be managed or 'juggled' in addition to their previous responsibilities. For example, one person with TBI expressed it as: '[partner] had to adopt the role of a carer, almost fulltime carer and going to work and looking after the kid[s]' (T)*

The changes to roles were met with a mixture of responses by the couples, from difficulties accepting or adjusting to the changes, to increased stress for the individuals caused by the imbalance. For example, couples described difficulties for people with TBI adjusting to loss of the 'bread winner' role or societal and cultural gender roles (e.g. *'But I think it's been difficult for him to... you know, there are... without being too gender stereotypical... he is [...] the man in the relationship. And I think that's been hard for him to... not be the more dominant person in the relationship' P*). For some couples this was associated with increased tension between them: *'cause he's not, he's not so willing to listen to me telling him something, "well, you're not the psychologist", "you're not a physiotherapist", "you're not a..." I said, 'no, but in this house at the moment I'm the expert' and he went, "you're always a bloody expert". And I said, "yeah, get used to it" (P)*. Some couples described adjusting more easily to the changes. For example, some individuals with TBI described appreciating and accepting their partner adopting the 'expert' role: *'So it wasn't just her wanting to give me advice it was the fact what she said was really worth listening to' (T)*

Examples of partners responses to the changes in roles included feeling *'bogged down'* (P), under increased pressure and feelings of stress related to the role changes: *'I can get a bit overwhelmed, bogged down and everything life throws at you and it can lead to feeling a bit exasperated with the relationship and feeling like... the caring side takes over the partnership that we had' (P)*.

### *Reciprocal support*

The concept of reciprocal support was examined through reports given by the people with TBI and their partners. Examples given by people TBI demonstrating their reciprocal support included: being more forgiving towards perceived partner's character flaws or tending to other duties to ease the load on their partner (e.g. filling up the car's petrol so their partner would not need to). Some individuals with TBI also described



trying to reciprocate emotional support to the same level and quality that they felt their partners had given to them (e.g. actively listening, quality advice, etc.). Some partners were able to recognise this, whereas others felt that they were less likely to approach the person with TBI for this level of support as they felt there had been a change in the individual's ability to provide this to the same level due changes in social skills, emotion recognition and other distractions: *'The hardest one, I have to say, is probably umm... the emotional support I used to get from him. And I see him try and sometimes it's there. [...] However, there was also a great lack of that sometimes'* (P)

In addition, some partners conveyed that the individuals with TBI were not able to support them to the same emotional level as they did before their injury. For some, this resulted in partners having an increased reliance on friends and family for emotional support. This, however, was depicted to change over time and with the person's recovery.

#### *Affection and sexual intimacy*

When asked about intimacy, half of all participants articulated changes following TBI (e.g. affection and sexual intimacy). Changes were attributed to TBI symptoms (e.g. physical or anger and aggression) and/or changes in relationship dynamics (e.g. role changes). Variations were sometimes noted between the types of attributions offered by partners and people with TBI. For example, one person with TBI said, *'you cannae... cannae expect to shout at her one minute and be all over you the next'* (T), whereas other people with TBI spoke about physical difficulties impacting on their ability to express intimacy, such as not being able to cuddle in bed due to pain (e.g. *'put my arm under her in bed'* T) or difficulties with mobility impacting on their ability to *'[hold] hands walking down the street'* (T). Partners generally expressed feeling less inclined to be affectionate or sexually intimate with the person with TBI due to feeling of frustration, tiredness or feeling *'worn down'* (P) as a result of the person with TBI's emotional and behavioural difficulties (e.g. increased aggression) or in response to changes in their roles (e.g. caregiver). As a result of the TBI, one person with TBI felt he had assumed the *'sickness'* role within his relationship, which he felt meant his partner perceived him to be unwell and therefore no longer able to be intimate.

Although changes in affection and sexual intimacy resulting from TBI induced feelings of frustration for some, this was not described as a significant issue for many of the couples as they were able to express their intimacy in other ways (e.g. affection, shared activities).

### *Time together*

None of the couples described significant changes in types of activities they did together (e.g. going out for coffee or walks together); however, many perceived changes in quality and quantity of shared activities since the TBI. The amount of time couples had to dedicate to shared activities were altered by factors such as loss of employment by the person with TBI, or partners' having less available time due to juggling multiple roles and responsibilities (e.g. parenting responsibility, increased working hours, etc.). One partner said the loss of employment for the person with TBI resulted in increased unstructured time at home, however the amount of time she had for shared activities remained unchanged. This was described to result in mismatched expectations and increased feelings of frustration, dissatisfaction and sadness between the couple. Other couples suggested that they appreciated the additional time to dedicated to shared activities and felt this brought them closer together: *'No, apart from as I say we do spend more time together, so we are... I do think we're closer together because eh we're together so much [laughs]' (P)*

Work was seen as significant barrier to the amount of time partners had to spend with the people with TBI and, consequently, their relationships. For some, the partners' increased working hours accommodated for the changes in the couples' financial statuses (e.g. *'instead of winding down, she [was] winding up'* T). Although some partners wondered whether they used work as a form of respite from their caregiving roles or from the person with TBI's emotional and behavioural difficulties, work was generally associated with feelings of anxiety for both partners and people with TBIs. For example, partners described anxiety related to leaving the person with TBI alone or feeling responsible for that person's social contact.

### 3.2.2. Perceived influences of and influences on relationship endurance following TBI

Couples' perceptions around the degree to which TBI changes impacted on their relationships varied from *'there is nothing there that puts pressure on us as a couple'* (T) to *'it's completely changed. It's completely different'* (P). Some participants mentioned having previously reflected on the sustainability of their relationship in light of the TBI changes. For example, one partner expressed having thought about *'at what point does it have to get to when I think, "this isn't... this isn't going to work"'* (P). Sometimes reflections around the relationship sustainability involved joint discussion and decision-making for some couples, as reported by this partner: *'We've had conversations in the last... year to say that... we want to... we want to survive; we want to get through this. We know the statistics are probably against us, but we want... we want to make this work and we want to figure out how to do that.'* (P). Based on this sample's interviews, themes emerged through inductive analysis that suggested couples' relationships endurance influenced and was influenced by to a mixture of pre-injury factors and post-injury processes within-relationship.

#### 3.2.2.1. Pre-injury factors

Pre-injury factors refer to themes/subthemes where participants described pre-injury qualities or traits that they felt influenced couples' responses and relationship experiences following TBI.

##### *Strong pre-injury relationships*

The concept of having a strong pre-injury relationship was endorsed by all participants who mentioned relationship strength. This seemed to reassure couples when they experienced challenges or had to cope with the difficulties presented by the TBI:

*'Had we had a weak relationship, she just couldn't have put up with me and it would have broken us...'* (T)

*'Umm... I think probably because we had a pretty solid footing beforehand and I think if that had been... dodgy umm or in any shape or form... fragile then it could easily... have made it very difficult for both of us to cope with it.'* (P)

### *Learning from the past*

The impact of TBI on couples' relationships for a few participants seemed to be moderated by their past experiences or pre-existing knowledge. Examples given by couples included previous relationships (e.g. divorce or relationship dissolution), couples shared stressful life experiences (e.g. moving) or having pre-existing knowledge of ABI or health-related difficulties (e.g. through non-immediate family lived experience or employment in a healthcare-related profession). Many implied that learning from these experiences shaped the way they approached their difficulties and also increased their psychological resilience to manage the changes. One person with TBI, for example, reflected on his previous 'bad [relationship] experience', which made him more mindful of '*not wanting to do that again*'. This encouraged him to 'think about the nature of [his current] relationship' and also helped to increase his appreciation towards his current relationship in light of the TBI-related difficulties the couple faced.

### *Having faith*

Spirituality emerged as a strong factor for a couple of participants, which they felt supported their ongoing relationships. They perceived that their faith supported their ability to cope in the acute stages, as well as encouraging ongoing '*patience and love to help and understanding eh to help your loved one*' (P) throughout the recovery process.

#### 3.2.2.2. Within relationship post-injury processes

The experience and consequences of TBI evoked a number of processes within the couples' relationships.

### *Relationship strength post-injury*

Nearly every participant made at least one spontaneous comment around the strength of their relationship. Relationship strength referred to the couples' evaluations of their relationship quality and was associated with feelings of closeness, love and/or commitment. Although interviewed separately, there appeared to be agreement and

similarities in the accounts given by people with TBI and their respective partners around relationship strength. Three couples believed that their relationships had become stronger since the TBI or they felt they were more aware of the strength of their relationships. For example:

*'I think... we both are, actually, are... not that we weren't committed before, but we're both more aware of... umm... [pause] I think how much we each invest in it... and especially when it has been hard. [...] that's the main result now... we're certainly as close, but probably closer.'* (P)

*'I felt good about them to start with but the injury tested us in a way that a weak relationship couldn't cope with and a strong relationship, I think, becomes stronger because of it'* (T)

Meanwhile, two couples reported feeling that their relationships were not as strong as they were previously (e.g. *'probably a wee bit. It's probably... not as good as it was. There's nothing wrong with it, but it's not as good as it was'* T), which was evoked feelings of loss (e.g. *'wanting the family to be very close, happy, which is how it was before.'* T). Among the two couples who described reduced relationship strength, one of the people with TBI did not think this affected the couples' feelings of commitment or that it would result in their relationship dissolution (e.g. *'never have a feeling that... the relationship will break up'* T), however he did express concerns that his partner may be *'missing out... losing out'* (T). Within the other couple, the person with TBI implied he was hopeful as the couple had a strong pre-injury relationship, which he felt they could eventually regain.

#### *Feelings of being understood and empathy*

On the whole, most of people with TBI conveyed feelings of being understood by their partners and feeling that their partners empathized with them, which in some cases was perceived to be advantageous to the person's recovery and their feelings towards their relationship. Some described feeling that their partners were also able to understand them in ways that other people were unable to. For example:

*'With [partner] she was taking a much more holistic view. Trying to understand what I was going through, not just in terms of umm a sort of physical symptom but an understanding of the emotional affect that, that it had on me. She was trying to*

*understand me and trying to help me umm... at a level that I think, really isn't something that the medics could have done.'* (T)

In contrast, some of the partners believed that they were not patient or understanding enough, particularly as time progressed (*'And uh... I'm not always as... erm... what's the word? Understanding. Get a bit frustrated'* P). A few specific examples were also given by a couple of people with TBI where they felt their partners had not, perhaps, fully appreciated or understood their individual TBI-related difficulties. For example, one person gave an example where he perceived that his partner had interpreted his fatigue as him not trying or being 'lazy'. One partner also reflected on this and stated that, for her, she felt there were limits to her ability to empathise as *'[she had] never been through it so it's difficult to empathise exactly how it is'* (P); however another partner stated that the person with TBI *'helps [her] understand his situation, just through... not that he's educating... he's educating me through just speaking to me'* (P) which she felt was part of their relationship *'teamwork'* (P).

#### *Appreciating their partners and partners' support and understanding*

More than half of the people with TBI articulated greater appreciation towards their partners. They described feeling appreciative of their partners' patience and strength of character, as well as their ongoing dedication, understanding, support and commitment to them and their relationships as illustrated by these statements:

*'I feel I've been very lucky to have somebody to stand by me like that'* (T)

*'Because I see someone whose qualities that I always knew about, but those qualities really helped me at a challenging time and make me love her all the more because of that.'* (T)

Several partners described feeling particularly appreciative towards their partners for their frequent visits and emotional support during their acute hospital admission. This was in spite of partners also dealing with their own feelings of shock and anxiety and also while juggling other demands (e.g. work, family, etc.) during this period. One person with TBI said his partner provided him with the motivation to persist in his recovery in order return home from hospital for which he felt indebted to her for: *'I was determined for that, so I do put a lot of my recovery down to will power. Umm which I*

*do again hold... [pause] I hold [partner] responsibility for giving that willpower, helping me... helping to provide that willpower and to that extend I do feel very indebted to her.'*  
(T)

People with TBI expressed their feeling of appreciation verbally to their partner, which was often acknowledged during their partners' accounts, and also behaviourally, where they tried to demonstrate their appreciation by reciprocating the support that their partners had given them: *'I think from my point of view, [partner] has supported me so much that I feel... that... I want to be able to support and help her when she needs it.'*  
(T).

### *Strengthening partnership, shared problems and experiences*

Partnership or strengthening of their partnership within their relationship was apparent for the majority of couples after TBI and seemed to contribute to their relationship endurance or strength. Partnership was associated with the belief that their experiences and difficulties went beyond the separate individuals, where these were more commonly seen as shared (e.g. shared experience or shared problems). For many, the sense of partnership also translated into shared coping (i.e. supporting each other). These were generally demonstrated through 'we' or 'us' statements, for example:

*'My brain injury was something that affected us as couple, it wasn't just a personal thing for me [...] it was something that we both experienced'* (T)

*'There are times when I feel that it's a bit unfair. Not on me. On us, you know'* (P)

*'They've affected us, but I don't think it's anything we can't eh resolve or put right'* (T)

*'We just take a day at a time and eh go on'* (P)

### *3.2.3. Contextual and other factors*

During the analysis of the interview, contextual and other factors (e.g. non-TBI attributions) emerged as possible moderators to the impact of TBI changes on couples' relationships.

### 3.2.3.1. Contextual factors

#### *Family and social system*

Although a number of participants acknowledged the wide impact of TBI on their families and wider systems, few examples were given around how the wider systems responses or types of supports influenced the couples' relationships. This was primarily seen to aid individual coping, which may have indirectly supported their relationships. Some concerns were raised around couples' relationships where children and anger difficulties were involved. These were discussed by both couples with and without children. Couples without children acknowledge the difficulties that this may present in hypothetical terms.

#### *Services*

On the whole, all couples described feeling satisfied with the services provided by the healthcare profession in the individual with TBI's rehabilitation and recovery, with only one criticism: that they would have liked to have more input. Two partners felt that this might have helped to relieve some of the pressure on them to adopt the 'expert' or 'therapist' role within their relationships. Very few examples were given that illustrated ways that healthcare professionals actively and directly acknowledged or supported the couple's relationship across the recovery process. A couple of examples of when they felt supported as a couple were given for the person's acute inpatient hospital care, such as: flexible visiting hours or healthcare professionals offering to support the partner to stay overnight at the hospital with the person with TBI. One partner noted that the difficulties within relationships was acknowledged by a neuropsychologist at a talk. She stated the neuropsychologist spoke about couples needing to 'understand when a relationship needs to end' and although not relevant to her, she felt it was important that this had been acknowledged.

None of the couples spoke about receiving direct formal input from healthcare professional to support their relationship following TBI. They noted possibly having opportunities at their rehabilitation sessions or healthcare professional review meetings



to mention any relationship difficulties they were experiencing. They stated that healthcare professions did not directly ask about their relationships and some described feeling that there was '*only one patient*' (T), which left little room for the needs of the partner ('*But no one was saying to her, "how hard is it for you having to deal with all that? You're the person who's having to spend most of your time now that you're at home, listening to the problem trying to provide advice, put up with the patient and all the problems he presents. You're trying to deal with all that. How is it for you?"*'; T) and their relationship. Two couples stated that if input for their relationship and for them as a couple '*had it been offered, umm, then you know, we would have gratefully accepted it and it would have helped*' (T), however they also recognise the pressure on services and the lack of resources available.

### 3.2.3.2. Non-TBI attributions

Across interviews, participants often described other factors, not related to the TBI, which they felt could also account for the possible changes in the couples' relationship. Examples of these included ageing or life transitions, gender stereotypes (e.g. '*I have to remind myself that what [partner] has maybe done isn't... isn't because of his brain injury and it's because he's a typical man*'; P) or pre-existing health difficulties (e.g. arthritis or sleep difficulties). For example, ageing or age-related factors were suggested to explain reduced sexual intimacy (e.g. menopause); whereas becoming parents or grandparents or children leaving home were associated with the amount of time couples had available or changed the way the couples prioritised and spent their time together. Interestingly, there were inconsistencies within couples to make non-TBI attributions with partners more likely to make these types of attributions than the people with TBI.

#### 4. Discussion

This study contributes to the currently limited dyad evidence-base exploring couples' experiences and relationships following TBI. The findings highlighted the complexities of trying to understand the impact of TBI on couples. Complexities which are exacerbated by the individualistic nature and consequences of TBI and the idiosyncratic responses from the dyad-individuals (i.e. person with TBI and their partner), as well as the complex interplay between these individuals within their relationships (e.g. even when there were similarities in the consequences of TBIs, this instigated different responses between and within couples' relationships). The interplay and interconnectedness between each individual person in the relationship and reflects a systems theory approach to understand the couples' experiences post-injury (see Verhaeghe, Defloor & Grypdonck, 2005). This suggests that change to one part of the system (e.g. a TBI) results in change for all due to complex, interpersonal interplay between the individuals in the systems (Gill *et al.*, 2011). In other words, an event, such as a TBI, results in changes that influences the individual and their partner, and how each individual responds to the changes will in turn have effect on the other respective person in the relationship. As TBIs can result in both lingering difficulties and difficulties that are constantly evolving and changing over time, it only further complicates the interplay within the system.

The combined deductive-inductive data analysis approach supported the data to be explored using pre-defined areas (e.g. communication, role change, sexual intimacy) associated with the research question and based on past research, whilst allowing for flexibility for data driven themes to emerge. Couples' responses to the deductive a priori interview questions associated with changes in relationships resulting from TBI symptoms (e.g. emotional and behavioural) and change in relationship dynamics (e.g. communication, role changes, affection and sexual functioning and intimacy, time together/shared activities) were consistent with those found by previous dyad studies conducted outside of the UK (e.g. Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner, 2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991). This was in spite of possible cultural differences, differences in methodological designs (e.g. grounded theory, content analysis) and sample demographics (e.g. mTBI or older adults) (e.g. Gill *et al.*, 2011; Hyatt, Davis & Barroso, 2015; Jacobsmeyer Werner,

2016; Layman, Dijkers & Ashman, 2005; Willer *et al.*, 1991). Unlike the previous studies, this study emphasized the impact of time since injury and TBI recovery on couples' relationships as a subtheme. This was influential to the partner's patience, coping and feelings of frustration. As time progressed, partners were noted feeling less patient and were more likely to allow themselves to get frustrated with person with TBI or with their situation (i.e. increase demands due to role changes). One explanation for the changes in partners' responses over time could be accounted for by the phased model of coping, which is said to share similarities with Kübler-Ross's five stages of grief model (see overview in Verhaeghe, Defloor & Grypdonck, 2005). Using this model, it is proposed that as time progresses and moves away from the index trauma event, couples' initial feelings of shock and relief associated with survival and/or feelings of denial reduce which increases their capacity to experience other emotions (such as frustration).

Interestingly, the 'moral dilemma' phenomenon (Lezak 1988; Wood 2006) was not explicitly expressed by the couples in this sample. Two people with TBI perceived that their relationships were not as strong as they were, however neither believed this would lead to their relationship dissolution and they also continued to be hopeful that their relationships would return to the same pre-injury level. A few partners and people with TBI acknowledged the vital input that their relationship had to the person with TBI, however this was not given as a reason for the couples to remain in their relationships. Most of the couples did not perceive that their relationships were in jeopardy and feeling more aware of their relationship strength or felt their relationships were stronger since the TBI. As opposed to 'moral dilemma', aspects of this appear to be consistent with the concept of post-traumatic growth, where post-traumatic growth is defined as '*positive psychological change experienced as a result of the struggle with highly challenging life circumstances or traumatic events*' (p.1; Calhoun & Tedeschi, 1999). Based on the current available findings, however, it would not be possible to conclusively determine the appropriateness of post-traumatic growth theory to understand the reported increased relationship strength and further research would be encouraged to explore this possible link in more detail.

It is important to acknowledged, however, that the lack of reports associated with 'moral dilemma' and high volume of reports associated with strengthening of the

relationships may be the result of biases in the sample (i.e. due to self-selection recruitment strategy or the relatively early timing of recruitment post-injury, where relationship dissolution has been suggested to increase with time; Wood & Yurdakel, 1997). None in this sample described having weak relationships pre-injury, which has been previously reported to influence couples' responses to the TBI, their perceptions around post-injury relationship strength and has been associated with relationship stability (Gill *et al.*, 2011). For example, one person with TBI in Layman, Dijkers and Ashman's (2005) study stated she had been considering separation from her partner pre-injury, which evoked negative feelings within her as her TBI had resulted in her having increased dependence on her partner.

Similarities were noted between the current finding and that of Layman, Dijkers and Ashman's (2005) study with regards to the couples' tendencies to use attributions as part of their sense-making process. Layman, Dijkers and Ashman (2005) explored experiences of older adult couples following TBI. Their findings suggested that couples were more likely to attribute their relationship changes following TBI to ageing or age-related issues. Couples in the current study also attributed their relationship changes to other non-TBI factors or TBI-related consequences; however slight variations were noted in the content of the attributions between the two studies. For example, one couple gave the example of becoming new parents the current study. These inconsistencies may be due to differences in the included samples age ranges. Layman, Dijkers and Ashman's (2005) study included participants from a discrete age range, whereas the current study did not place limits over the ages of the adult participants, which produced a sample that was approximately 18.5 years younger than those in Layman, Dijkers and Ashman's (2005) study. Layman, Dijkers and Ashman (2005) hypothesized that their samples attributions resulted from couples misattributing symptoms of TBI to ageing because of similar and overlapping presentations. In addition, they concluded that the general lack of understanding towards TBI by the general population exacerbated people's tendencies towards misattributions. The latter perspective could hold value towards understanding the current findings, however the former is less likely to play a specific role for this sample. One other reason that may explain the perpetuated process of making attributions towards non-TBI related factors may be associated with the role of denial as a protective coping process (Verhaeghe, Defloor & Grypdonck, 2005).

#### 4.1. Study limitations

Although this study provided some interesting findings to research within the area of couples' experiences and relationships following TBI, caution is encouraged towards the interpretations of findings, due to limitations within the study. For example, the sample size was relatively small and the study's response rate was relative low compared with other studies (e.g. 38% response rate in Layman, Dijkers & Ashman, 2005). Based on accounts from a few couples who took part in the study, there was the sense that the topic was quite sensitive and private (*'I think for me, although, I've talked probably far too much about these things, they... they are private'* T). This may have been particularly poignant considering the target population and possible gender and/or cultural biases influencing potential participants' willingness to engage in a potentially sensitive and emotive topic (e.g. 'males', and/or 'Scottish males') (Perlesz *et al.*, 1999; Verhaeghe, Defloor, Grypdonck, 2005). For couples in this study's sample, they felt encouraged to participate as they perceive the topic to be of particular importance in spite of its private and sensitive nature. Bearing this in mind and the recruitment self-selective nature, the sample may also have been biased towards more cohesive couples.

Other potential biases in the sample may result from recruitment from a single site, the inclusions and exclusion criteria (e.g. sufficient communicate for participation in the interview, heterosexual couples who remain in the same cohabiting relationship). For example, it would not be possible to draw conclusions for couples who experienced severe receptive and expressive communication difficulties; couples who were no longer co-habiting; couples of other sexual orientations; or for couples who have significant relationship difficulties that has resulted in relationship separation or dissolution. Although purposive sampling was used to encourage potential participants were selected on their ability to provide richness of information to the research question, the means to capture the 'right' kind of participants to provide information rich data remains debated (e.g. selection based on sample demographic vs. brain injury factors vs. recovery-based experiences). Heterosexual males with TBI and their female partners had been included in this study due to previous research suggesting possible discrepant experiences for women with TBI as well as male partners (e.g. Brunsden *et al.*, 2017; Hammond, Davis, Whiteside, Philbrick & Hirsch, 2011; Willer *et al.*, 1991).

Another limitation may result from the interview methodology for data generation and the potential role of social desirability or denial influencing disclosures. In Verhaeghe DeFloor and Grypdonck's (2005) review denial was discussed having a possible protective value for people after a TBI, where they also concluded that '*achieving acceptance [was] neither realistic nor desired*' (p.1007) due to ongoing adaptation processes. This, however, is unlikely to be limited to qualitative research alone (i.e. also affect quantitative research). Meanwhile, the likelihood of participants providing socially desirable responses was slightly reduced as the interviewer was not known to the participants prior to their participation in the study.

The multiple coding approach used in the framework analysis' indexing and pilot charting was not conducted independently between coders, which could introduce bias in the development of the initial chart. This approach, however, had been use previously by qualitative researchers and was more responsive to the resource constraints in the study (Barbour, 2001). Although this multiple coding approach was taken to reduce reliance on the researcher's interpretations, the data analysis was still likely to be affected by the interview process and the interaction between the interviewer and the participant, as well as the researcher's own experiences and previous knowledge within the area (e.g. psychological perspectives).

#### 4.2. *Recommendations for future research*

With the aforementioned limitations in mind, a number of recommendation were encouraged: firstly, it is strongly encouraged that further dyadic research is conducted will contribute to the systemic and holistic picture of experiences and difficulties faced by couples after TBI (Godwin *et al.*, 2011; Blais & Boisvert, 2005). Inclusion of the people with TBI and their partners offer different perspectives and approaches to the same area of interest. It also allows and any interactional processes between them to be better understood. Secondly, it was recommended that future studies consider recruit from multiple sites and consider recruiting a more broadly representative sample (e.g. same-sex couples, females with TBI, etc) (e.g. Gill *et al.*, 2011; Brunsden *et al.*, 2015). It is also important to recognise that as further variables are explored or included, larger samples sizes may be required to encourage sufficient data saturation.

Thirdly, triangulation (see Hammond *et al.*, 2011) and other types of data generation interviews may also be considered (e.g. focus groups, joint interviews) (Hyatt *et al.*, 2015; Willer *et al.*, 1991). Fourthly, longitudinal studies would help to gain a better understanding of the changes in couple's experiences and relations as time progresses. This may be particularly important when considering the needs of each individual and as relationship stability may change as time progresses (Wood & Yurdakul, 1997). Although not the focus within this study, the impact on the wider family (i.e. children) was also recognised by the couples. For future family research, it is encouraged that researchers continue to differentiate between the family different member's experiences.

#### *4.3. Recommendations for clinical practice*

Due to the previously mentioned limitations, the following suggestions for clinical practice should be interpreted with caution. The traditional service configuration generally focuses on the concept that there is a single service user, which in the case of TBI, is the person who has suffered the injury. This configuration is understandable in light of the high demands on services and scarce resource availability, however the premise underpinning this model may be flawed. With growing recognition towards more systems theory models (as encourage by the current study's findings), it is recognised that the traditional service configuration is only likely to address one part of the whole system (i.e. the person with TBI) and, possibly unintentionally, ignore the other aspects of the system (e.g. partner and interaction or interplay between the couple). For some, this could be detrimental for the person with TBI's recovery as poor functioning in the other parts of their system may have direct and/or indirect consequence for that person. Ideally changes in the current service provision would result in services directed towards the individual with TBI, their partner and the couple. This approach would also need to be responsive to the changes experienced by the dyad-individuals over time and course of recovery (e.g. medical stabilisation and acute stages, vs. chronic). Therein lies two vital unanswered questions: firstly, how applicable would it be to facilitate this in practice, particularly when funding and resource availability remains limited? Secondly, who should be considered as the 'service user'?

Based on this study's findings, couple's relationships may benefit from support with anger at the level of the person with TBI. This would include support to recognise their feelings of anger as well as developing coping strategies to manage the outbursts. The couples in this sample also valued partners involvement in formal rehabilitation sessions (e.g. physiotherapy, neuropsychology), as their partners were able to help the individual with TBI overcome possible cognitive limitations that would have acted as a barrier to the person with TBI being able to continue their rehabilitative progress outside of the formal therapy session. With this in mind, couples where the partner is involved in the person's rehabilitation, they would likely benefit from guidance and support in setting realistic expectations around the service's availability, provision and limitations (i.e. boundaries).

Wood (2006) acknowledged the 'double whammy' (p.139) that partners can experience due to the lack of partner directed service support. He suggested that this can result in partners not only having to learn to cope with the changes in the person with TBI but also deal with feeling let down by services. The findings in this study implied that partners would generally benefit from increased recognition towards their currently unmet needs, as well as possibly directing support to helping them to develop ways of coping and adjusting to the changes resulting from the TBI (e.g. TBI symptoms and changes in roles).

With regards to couple's relationships, it was implied that increased awareness of healthcare professionals to possible relationship difficulties would be advantages. In practice, this would be exhibited by couples feeling as though they have opportunities to raise relationship issues if necessary, as well as healthcare professionals asking directly. Hypothetically, this may also require additional training for staff to increase awareness towards couple's potential difficulties and/or training to increase confidence to manage situation where couples do raise issues. Moreover, this would also require there to be clear service pathways for couples should they need more formal support.

For more detailed guidance around service recommendations, it is strongly recommended that: firstly, further research is conducted with the primary goal around exploring the needs of the couple (both individually and jointly); and secondly, where



interventions are identified, their efficacy and acceptability to the service users are evaluated.

## **5. Conclusion**

TBI is not solely experienced by any single individual, but rather is experienced through a complex interplay between the person who has suffered the TBI, their partner and within the couple's relationship. This interconnectedness also has an influence on how they respond to and manage the changes, which in turn can feed back into the way they experience the TBI. Both their experiences and responses to the changes can also be influenced by their relationship characteristics (e.g. pre-injury relationship, feelings of appreciation) as well as other types of attributions that the couple uses to help make sense of changes that they experience. This can raise issues for healthcare services around how they view and approach the individual with TBI, their partner and the couple's relationship during the recovery and rehabilitation process.

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## **Conflicts of interest**

The authors declare no conflict of interest with respect to this paper.

## **Declaration of Interest**

n/a

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## APPENDICES

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**Appendix 1. Eligible studies not sampled for review**

<b>Excluded study</b>	<b>Reason for exclusion</b>
Robins, N. (2012). Exploring Intimacy After Traumatic Brain Injury (TBI) for TBI Survivors and Their Partners. University of Illinois: Chicago, USA.	Subsequently published: Gill, C., Sander, A.M., Robins, N., Mazzei, D., & Struchen, M.A. (2011). Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners. <i>J head Trauma Rehabil</i> , 26, 1, 56-68.

## Appendix 2. Appraisal tool for Cross-Sectional Studies (AXIS; Downes, Brennan, Williams & Dean, 2016)

### Appraisal of Cross-sectional Studies

	Question	Yes	No	Don't know/ Comment
<b>Introduction</b>				
1	Were the aims/objectives of the study clear?			
<b>Methods</b>				
2	Was the study design appropriate for the stated aim(s)?			
3	Was the sample size justified?			
4	Was the target/reference population clearly defined? (Is it clear who the research was about?)			
5	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?			
6	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?			
7	Were measures undertaken to address and categorise non-responders?			
8	Were the risk factor and outcome variables measured appropriate to the aims of the study?			
9	Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?			
10	Is it clear what was used to determine statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)			
11	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?			
<b>Results</b>				
12	Were the basic data adequately described?			
13	Does the response rate raise concerns about non-response bias?			
14	If appropriate, was information about non-responders described?			
15	Were the results internally consistent?			
16	Were the results presented for all the analyses described in the methods?			
<b>Discussion</b>				
17	Were the authors' discussions and conclusions justified by the results?			
18	Were the limitations of the study discussed?			
<b>Other</b>				
19	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?			
20	Was ethical approval or consent of participants attained?			



## Introduction

The introduction serves to establish the context of the work that is about to be presented in the text of the paper. Relevant primary literature should be discussed and referenced throughout the introduction. The history and current understanding of the problem being researched should be presented. This should be concluded giving a rational as to why the current study is being presented and what the aims and/or hypothesis under investigated are [2,3].

## Aims

The aim(s) of the study tells us if the study addresses an appropriate and clearly focused question. If the aim is not clearly stated or not stated at all, it will be difficult and in some cases impossible to assess the extent to which the study objectives were achieved. Ideally, an aim should be stated both at the beginning of the abstract and at the end of the introduction [3]. If the answer to question 1 is no, then it will make it difficult to assess some of the other questions in the critical appraisal process.

## Methods

The methods section is used to present the experimental study design of the paper. The methods should be described clearly in easy to understand language and clearly identify measures, exposures and outcomes being used in the study [4]. More specific issues are addressed below.

## Study Design

Question 2 is used to assess the appropriateness of using a cross-sectional study to achieve the aim(s) of the study. Cross-sectional studies are observational studies that provide a description of a population at a given time, and are useful in assessing prevalence and for testing for associations and differences between groups [5]. Examples of cross-sectional designs include point-in-time surveys, analysis of records and audits of practice [6]. The reader should try and decipher if a cross-sectional study design is appropriate for the questions being asked by the researcher.

## Sample Size Justification

Sample size justification is crucial as sample size profoundly affects the significance of the outcomes of the study. If the sample size is too small then the conclusions drawn from the study will be under powered and may be inaccurate. This can occur by failing to detect an effect which truly exists (type II error) sometimes referred to as a “false negative”. The probability of a type I error is also taken into account when determining sample size. A type I error is drawing significant conclusions when no real difference exists and is a function of the p-value (see Statistics section below) sometimes referred to as a “false positive”.

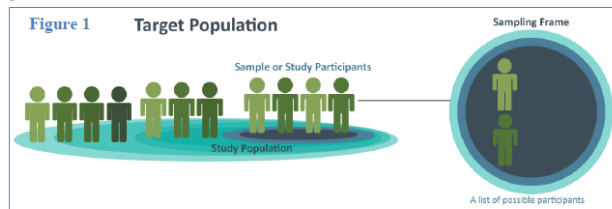
Question 3 asks if sample size justification was reported, but it should also be clear what methods were used to determine the sample size. In some cases clustering of observations within groups can occur (e.g. patients within hospitals or livestock within herds) and this should be taken into account if sample size has been determined. It should be clear whether the inferences drawn actually relate to the attributes for which the sample size was calculated [7]. If sample size justification isn't given or restrictions make it difficult to reach the desired sample size then this should be declared in the text.

## Target (Reference) Population

The target or reference population is the overall population that the research is directed towards. When doing a cross-sectional study, a target population is the overall population you are undertaking the study to make conclusions about or the population at risk of acquiring the condition being investigated [8–10] e.g. the total female population in the UK, or all dogs in the USA with cardiovascular disease. (See Figure 1) Question 4 asks if this is clearly defined in the study. It is important that this is understood both by the researcher and the reader; if it is not clearly defined then inferences made by the researcher may be inappropriate.

## Sampling Frame

As a reader you need to determine if the sample frame being used is representative of the target population. The study population should be taken from the target population; units from this study population have information that is accessible and available which allows them to be placed in the study. The sampling frame is the list or source of the study population that the researcher has used when trying to recruit participants into the study (Figure 1). Ideally it should be exactly the same composition or structure as the target population. In practice it is generally much smaller, but should still be representative of the target population. Generally, for convenience, the sampling frame is a list of units that are within the target population e.g. list of



telephone owning households, computerised patient records etc. A sample of units is selected from the study population to take part in the study and is generally only a small proportion of the study population (see Sample Selection below) - this proportion ratio is known as the sampling fraction. It is very important that the sampling frame is representative of the target population as results from the study are going to be used to make assumptions about the target population [8–10].

Convenience sampling can be carried out in some situations and are used because the participants are easy to recruit. Convenience samples generally lead to non-representative or biased samples and therefore cannot be used to make assumptions about the characteristics of the target population [11]. Convenience samples are often used for pilot or analytical studies where the need for a representative sample is not required [12], however the authors should make this clear in the text.

### ***Census***

A census is where the target population and the study participants are the same at the time the census is taken. In theory questions 5, 6 and 7 don't apply to census studies. However even if a study is described as a census it should be very clearly stated where the study participants have been recruited from, and the reader should make the decision if the study truly is a census. A census may include all the population from the sample frame, but not all the target population; in this scenario questions 5 to 7 need to be addressed.

### **Sample Selection**

Question 6 is used to establish how the researchers got from the sample frame to the participants in the study. It examines the potential for selection bias and how the researcher developed methods to deal with this. The sample selection process is important in determining to what extent the results of the study are generalizable to the target population. For question 6 we are looking in depth at how the sample (study participants) was selected from the sampling frame. It is important to know if there were any inclusion or exclusion criteria used, as inappropriate criteria can dramatically shift how representative the sample is of the target population [8,10,13].

Selection bias can occur if every unit in the sample frame doesn't have an equal chance of been included in the final study [11,14]. Randomisation is used to ensure that each participant in the sampling frame has an equal chance of being included in the sample. If methods of randomisation are not used, not described or are not truly random, this may lead to a non-representative sample being selected and hence affect the results of the study [10,11].

There are many other situational issues to take into account when determining if the population in the sample is likely to represent the target population. Often these issues are outside the control of the researcher, but sometimes are overlooked. One such issue is the healthy worker effect which is a well-known phenomenon in human cross-sectional studies [13]. An example of this is, a researcher trying to do a cross-sectional study to determine health factors in a factory population and decides to sample from workers at work on a particular day. Unfortunately there is a tendency to over select healthy workers as ill workers may tend to be at home on the day of selection. This will in turn

lead to inferences been made about the health of the worker population but is only relevant to healthy workers and not ill workers. A veterinary example of this is a researcher trying to do a cross-sectional study to determine health factors in the general dog population and decides to sample from a local park. Unfortunately there is a tendency to over select healthy animals as sick animals will tend to be left at home and not taken for a walk. This will in turn lead to inference been made about the health of the dog population but is only relevant to healthy dogs and not sick dogs.

Self-selection is another example of selection bias that can be introduced and should be assessed [13]. For example, when using a postal questionnaire to examine eating habits and weight control, people who are overweight might read the survey and be less inclined to complete and return the survey than those with normal weight leading to over representation of people with normal weight. Similarly, if using a postal questionnaire to examine mastitis levels on cattle farms, farmers that have a high somatic cell counts (SCC) might be less inclined to complete the survey than those with normal or low SCC leading to over representation of farms with good SCC (see Non-responders below).

### **Non-responders**

Non-response in cross-sectional studies is a difficult area to address. A non-responder is someone who does not respond either because they refuse to, cannot be contacted, or because their details cannot be documented. As a rule, if participants don't respond it is often difficult and sometimes impossible to gain any information about them. However other baseline statistics may exist that can be used as a comparator to assess how representative the sample is [14] e.g. age, sex, socio-economic classification. Methods used, if any, should be well described so that the results from the analyses can be interpreted. This is important as non-responders may be from a specific group, which can lead to a shift in the baseline data away from that group. This shift can lead to results that don't represent the target population. In some situations the sampling frame doesn't have a finite list or a fully defined baseline population. This also makes it difficult, and in some cases impossible, to quantify non-response and it may be inappropriate to do so in these situations. If the researchers are using non-defined populations this should also be declared clearly in the materials and methods section [15,16].

### **Measurement Validity & Reliability**

Measurement validity is a gauge of how accurately the study measurements used assess the concepts that the researcher is attempting to explore. Measurement reliability is a gauge of the accuracy of the measurements taken or the procedures used during the study. Question 8 is used to address the concepts of measurement validity, and is specifically aimed to address the appropriateness of the measurements being used.

The importance of measurement validity is that it gives weight to applying the statistical inferences from the study to members of the target population. If inappropriate measures are used in the study it could lead to misclassification bias and it will be difficult to determine to what extent the study results are relevant to the target population [12,17].

Question 9 is an attempt to gauge the measurement reliability of the study measures. Measurements must be able to be reproduced and produce identical results if measured repeatedly, so that the measurements would be exactly the same if performed by another researcher. With this in mind, the measurements must be of international or globally accepted standards (e.g. IU standards) where possible and appropriate. If they are being used for the first time they must be trialled, or in the case of questionnaires, they should be piloted before being used.

### Statistics

While interpretation of statistics can be quite difficult, a basic understanding of statistics can help you to assess the quality of the paper. Often many different methods can be used correctly to test the same data, but as there is such a wide range available, knowing what tests are most appropriate in particular situations can be hard to decipher. There is an expectation that the researcher has this understanding or has at least sought statistical assistance to ensure that the correct methods are used. Therefore for question 10 the emphasis for the reader is that the statistical methods, software packages used and the statistical significance levels are clearly stated even if the paper is just presenting descriptive statistics. The statistical significance level is usually described as a p-value. In most cases the p-value, at which the null hypothesis is rejected, is set at 0.05. The higher the p-value is set the greater the possibility of introducing a type I error. Confidence intervals should also be declared with p-values or instead of p-values as an indication of the precision of the estimates. It is usual to present a confidence interval of 95% which means that the researchers were 95 per cent confident that the true population value of the outcome lies between these intervals. This can be used to compare groups where an overlap would suggest no difference and a gap between confidence intervals would suggest a difference (Figure 2).

### Overall Methods

Question 11 asks if the methods are sufficiently described to enable them to be repeated. If there are sections or even small pieces of information missing it could make a great

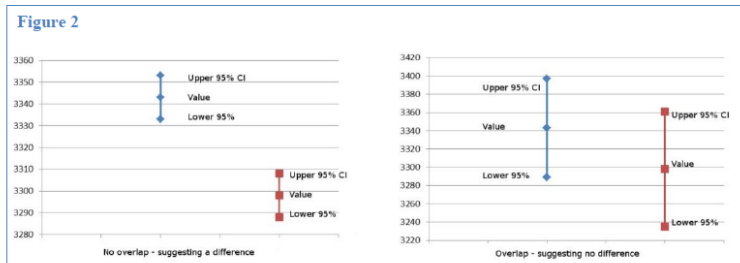
difference for the reader when interpreting the results and the discussion as they may be unsure if the correct methods are being used.

## Results

The results section of a paper is solely for the purpose of declaring the results of the data analysis and no opinion should be stated in this section. This gives the reader the opportunity to examine the results unhindered by the opinion of the researcher. It is important for the reader to form their own ideas or opinions about the results before progressing to the discussion stages.

### Basic Data

Question 12 asks for a description of the basic data. Basic descriptive analysis aims to summarise the data, giving detailed information about the sample and the measurements taken in the study. The basic data gives an overview of the process of recruitment and if the sampling methods used to recruit individuals were successful in selecting a representative sample of the target population. If the



sampling methods are unsuccessful in selecting a representative sample of the target population, those participants included in the study can often be different to the target population; this leads to inaccurate estimates of prevalence, incidence or risk factors for disease. Descriptive data of the measurements taken in the study give an overview of any differences between the groups, and may give insight into some of the reasons for statistical inferences that are made later in the paper.

### Response Rate

As stated previously it can often be difficult to deal with non-responders. Question 13 requires that there is some attempt made to quantify the level of non-response by the researchers and asks the reader to interpret if the response rate is likely to lead to non-response bias. Question 14 is examining if any information on non-responders was available and if so were they comparable to those that did respond as this could help in answering question 13. Non-response bias occurs if the non-responders are substantially different to the rest of the population in the sample [15].

### Internally Consistent Results

Question 15 is an exploration of the basic data and asks that the reader spends some time exploring the numbers given in the results; in the text, figures and tables. Information about the level of missing data should also be declared in the results. It is important to check that the numbers add up in the tables and the text. If the study has recruited 100 participants, the tables and the text should include data about 100 participants. If not, the missing data should be clearly declared and the reason for its non-appearance explained.

### Comprehensive Description of Results

It is important to check that all the methods described previously lead to data in the results section (question 16). Sometimes the results from all analyses are not described. If this is noted it will be unclear whether the researcher found non-significant results or just didn't describe what was found. If there are results missing that you would expect to find, there is a concern that these missing results may not have been what the researcher wanted to see and hence the authors have omitted them. It is also important that the significance level declared in the methods is adhered to. As the reader, it is important to watch out for phrases such as "tended towards significance" in the text, and if these are used to pay close attention to the results.

### **Discussion**

The discussion of a paper should summarise key results of the study objectives. It should give an overall interpretation of the results of the study keeping in mind the limitations and the external validity of the document. The discussion section should also address both significant and non-significant findings of the study and make comparisons with other research, citing their sources [2,4].

### Justified Discussions and Conclusions

In question 17 there is an expectation that the researcher gives an overall summary of the main findings of the study and discusses these in detail. It is important that the reader considers the study as a whole when reading the researcher's conclusion. If the researcher's conclusion is different or is more definitive than the study suggests it should be, it can be an indication that the researcher has misunderstood their own study or has other motives or interests for coming to that conclusion.

It is up to the reader to explore the discussion fully in order to answer question 17. The following points should be taken into account:

#### ***Aim***

In the discussion section the researcher should discuss all results that pertain to the overall aim of the study, even if they are not significant. If some results are overlooked in the discussion it could suggest that the researcher either doesn't believe the results, or doesn't want to draw attention to

controversial discoveries from the study and may therefore be giving a biased overview of the research conducted.

#### ***Selection Bias***

There is an expectation that the researcher discusses selection biases and takes these into account when interpreting the results of the study. This also gives a clear view of whether the researcher has an overall understanding of the study design. (See notes on selection bias in the methods section).

#### ***Non-response***

Was there an interpretation of the results that included non-response? This is particularly important if the response rate was low, as non-responders may be a specific group, and lead to a shift in the baseline data (See notes on non-response in the methods section).

#### ***Confounding***

Confounding is a major threat to the validity of practical inferences made from statistical analyses about cause and effect. Confounding occurs when the outcome of interest is associated with two different independent variables and one of those variables is closely associated with the outcome only because it is closely associated with the other variable (confounder). This can sometimes be accounted for using statistical methods however sometimes these associations are missed because the confounder isn't measured or isn't considered to be a confounder in the analyses. What then happens is an erroneous conclusion is made; that the variable might have a causal relationship with the outcome. The researcher should consider confounding both in the analyses and in the interpretation of the results [18]. An example would be where in a study on cancer a researcher concludes that increased alcohol intake causes lung cancer; however there was confounding in the sample that the researcher didn't discover. People in the study that were inclined to drink more alcohol were also inclined to smoke more (the confounder) and smoking was the cause of lung cancer not increased alcohol intake. Similarly, a study was undertaken to examine surgical deaths in cats. The researcher concluded that cats that had gaseous anaesthesia were more likely to die during surgery than those that had just injectable anaesthesia. There was confounding in the sample: cats that underwent surgery using gaseous anaesthesia were more likely to be ill or undergoing major surgical procedures (the confounders) and this was the cause for cats being more likely to die during surgery and not the use of gaseous anaesthetics.

#### ***Non-significant Results***

Discussing non-significant results is as important as discussing significant results and should also be included in the discussion, especially if they have a direct association with the aim being investigated. Non-significant results can be influenced by factors associated with study design and



sample size. If there are biases introduced during the study design this can lead to non-significant results that in reality may be significant (this can work the other way around as well). If there are only small differences between groups, non-significant results may be apparent because the sample size is too small (see sample size justification). Again it is important that the researcher has a clear understanding of this and conveys that in the discussion.

### Limitations

In question 18 we explore whether limitations are discussed. Unfortunately all forms of research have some limitations. The question here is whether the researcher has an understanding of the limitations involved in their study design. If this issue is not explored, this is cause for concern that the limitations don't stop at the design and that the researcher has a poor understanding of the study as a whole.

### Other

### Conflicts of Interest

It is very important that conflicts of interest or bodies involved in funding the study are declared in the text (question 19). This can give an impression as to background reasons for carrying out the study. Where studies are funded by a specific agency the researcher may unconsciously interpret in favour of the agencies' ideals; if the researcher has worked in a specific area their own ideas and beliefs may affect the interpretation of the results. It is up to the reader to identify these and come to the conclusion as to whether these conflicts of interest are relevant or not. This can be declared in different areas of the text and should be stated.

### Ethical Approval

Question 20 deals with ethical approval and participant consent. It is important that these are sought before carrying out research on any animal or person.

### References:

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### Appendix 3. Joanna Briggs Institute's Critical Appraisal Checklist for Qualitative Research (JBI-QARI; Joanna Briggs Institute, 2014)



#### JBI Critical Appraisal Checklist for Qualitative Research

Reviewer \_\_\_\_\_ Date \_\_\_\_\_

Author \_\_\_\_\_ Year \_\_\_\_\_ Record Number \_\_\_\_\_

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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## Discussion of Critical Appraisal Criteria

*How to cite:* Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc.* 2015;13(3):179–187.

### 1. Congruity between the stated philosophical perspective and the research methodology

Does the report clearly state the philosophical or theoretical premises on which the study is based? Does the report clearly state the methodological approach adopted on which the study is based? Is there congruence between the two? For example:

A report may state that the study adopted a critical perspective and participatory action research methodology was followed. Here there is congruence between a critical view (focusing on knowledge arising out of critique, action and reflection) and action research (an approach that focuses on firstly working with groups to reflect on issues or practices, then considering how they could be different; then acting to create a change; and finally identifying new knowledge arising out of the action taken). However, a report may state that the study adopted an interpretive perspective and used survey methodology. Here there is incongruence between an interpretive view (focusing on knowledge arising out of studying what phenomena mean to individuals or groups) and surveys (an approach that focuses on asking standard questions to a defined study population); a report may state that the study was qualitative or used qualitative methodology (such statements do not demonstrate rigour in design) or make no statement on philosophical orientation or methodology.

### 2. Congruity between the research methodology and the research question or objectives

Is the study methodology appropriate for addressing the research question? For example: A report may state that the research question was to seek understandings of the meaning of pain in a group of people with rheumatoid arthritis and that a phenomenological approach was taken. Here, there is congruity between this question and the methodology. A report may state that the research question was to establish the effects of counselling on the severity of pain experience and that an ethnographic approach was pursued. A question that tries to establish cause-and effect cannot be addressed by using an ethnographic approach (as ethnography sets out to develop understandings of cultural practices) and thus, this would be incongruent.

**3. Congruity between the research methodology and the methods used to collect data**

Are the data collection methods appropriate to the methodology? For example:

A report may state that the study pursued a phenomenological approach and data was collected through phenomenological interviews. There is congruence between the methodology and data collection; a report may state that the study pursued a phenomenological approach and data was collected through a postal questionnaire. There is incongruence between the methodology and data collection here as phenomenology seeks to elicit rich descriptions of the experience of a phenomena that cannot be achieved through seeking written responses to standardized questions.

**4. Congruity between the research methodology and the representation and analysis of data**

Are the data analyzed and represented in ways that are congruent with the stated methodological position? For example:

A report may state that the study pursued a phenomenological approach to explore people's experience of grief by asking participants to describe their experiences of grief. If the text generated from asking these questions is searched to establish the meaning of grief to participants, and the meanings of all participants are included in the report findings, then this represents congruity; the same report may, however, focus only on those meanings that were common to all participants and discard single reported meanings. This would not be appropriate in phenomenological work.

**5. There is congruence between the research methodology and the interpretation of results**

Are the results interpreted in ways that are appropriate to the methodology? For example:

A report may state that the study pursued a phenomenological approach to explore people's experience of facial disfigurement and the results are used to inform practitioners about accommodating individual differences in care. There is congruence between the methodology and this approach to interpretation; a report may state that the study pursued a phenomenological approach to explore people's experience of facial disfigurement and the results are used to generate practice checklists for assessment. There is incongruence between the methodology and this approach to interpretation as phenomenology seeks to understand the meaning of a phenomenon for the study participants and cannot be interpreted to suggest that this can be generalized to total populations to a degree where standardized assessments will have relevance across a population.



**6. Locating the researcher culturally or theoretically**

Are the beliefs and values, and their potential influence on the study declared? For example:

The researcher plays a substantial role in the qualitative research process and it is important, in appraising evidence that is generated in this way, to know the researcher's cultural and theoretical orientation. A high quality report will include a statement that clarifies this.

**7. Influence of the researcher on the research, and vice-versa, is addressed**

Is the potential for the researcher to influence the study and for the potential of the research process itself to influence the researcher and her/his interpretations acknowledged and addressed? For example:

Is the relationship between the researcher and the study participants addressed? Does the researcher critically examine her/his own role and potential influence during data collection? Is it reported how the researcher responded to events that arose during the study?

**8. Representation of participants and their voices**

Generally, reports should provide illustrations from the data to show the basis of their conclusions and to ensure that participants are represented in the report.

**9. Ethical approval by an appropriate body**

A statement on the ethical approval process followed should be in the report.

**10. Relationship of conclusions to analysis, or interpretation of the data**

This criterion concerns the relationship between the findings reported and the views or words of study participants. In appraising a paper, appraisers seek to satisfy themselves that the conclusions drawn by the research are based on the data collected; data being the text generated through observation, interviews or other processes.

#### Appendix 4. Confirmation of Caldicott and NHS NOS ethical review and approval

CG/2017/052



### APPLICATION FORM FOR CALDICOTT APPROVAL FOR USE OF PATIENT IDENTIFIABLE DATA

After completion please return this form to

Caldicott, Information Governance, NHS Grampian, Rosehill House, Foresterhill Site,  
Cornhill Road, Aberdeen AB25 2ZG

Email: [nhsq.caldicott@nhs.net](mailto:nhsq.caldicott@nhs.net)

**Project Title** Couples' experiences following a traumatic brain injury

**Description:**

*Aim:* to explore couple's experiences following a brain injury.

*Analysis:* qualitative research

*Method:* Potential participants will be initially identified by their clinician's and be invited to opt-in to the project. After opting into the study, written informed consent will be requested from participants with the brain injury to gain access to their medical notes regarding their brain injury. Only unidentifiable information will be used in the final results (including quotations).

*Ethics approval:* The project has received favourable opinion from North of Scotland (1) Research Ethics Committee.

*Dissemination:* All final results will be unidentifiable. The project will be completed as part of a doctoral thesis (University of Edinburgh) and will be reported and disseminated as such. Further publication will also be sought in a peer reviewed journal. The results may also be used to develop a patient information leaflet, pending consent from participants involved in the study.

**Name of Applicant:** Nicole Chadwick, Trainee Clinical Psychologist

**Address:** Department of Neuropsychology, Room 2.21, Ashgrove House, Forresterhill Aberdeen AB25 2ZN

**Tel No** 01224 554699

**Email address:** Nicole.Chadwick@nhs.net

**Name of organisation receiving data:** NHS Grampian

**and their Data Protection Registration Number:** \_\_\_\_\_

**What patient identifiable information are you looking to use?**

CHI Number	x
------------	---

Application Number .....(for office use only)

1



Forename	X
Surname	X
Initials	
Date of Birth	
Address	
Postcode	
Other, please specify	
Gender	X
Age	X
Nationality	X
Highest level of education	X
Employment Status	X
Occupation status (current and prior to injury)	X
Length of relationship	X
Relationship status	X
Cohabiting status (current and prior to injury)	X
Presence of children (<18 years)	X
Type of injury	X
Time since injury	X

Application Number .....(for office use only)

2

**How will the data be transferred?**

- Paper records ☐  
Computer records ☐

Potential participants will be initially screened and invited to opt-in to the study by clinician's who work with them. Once opted-in, informed consent will be collected from participants to gain access to their person identifiable data (e.g. details about their brain injury) and to record the interviews. No person identifiable data will be used in the database, or final results (including quotations, which will be made unidentifiable). The unidentifiable database will be kept by the applicant and will be treated on strict a confidential and need-to-know basis and in line with all necessary data protection procedures and policies.

(Note – patient/user identifiable data must not be transferred via e-mail unless anonymised, encrypted or using secure NHS network i.e. nhs.net)

**Who else will have access to the data?**

(If data recipients are not employed by the NHS please state whether NHS honorary contracts are in place. If not – detail confidentiality agreements)

Clinical supervisor: Dr Maggie Whyte, Consultant Clinical Psychologist  
Department of Neuropsychology, Room 2.21, Ashgrove House, Forresterhill Aberdeen  
AB25 2ZN

Academic supervisor: Dr Paul Graham Morris, Lecturer in Health Psychology  
Clinical and Health Psychology, School of Health in Social Science, University of  
Edinburgh, Teviot Place EH8 9AG

Academic supervisor: Dr Emily Newman, Health Psychology Lecturer/Research Director  
in Clinical Psychology and Postgraduate Research Director in Clinical Psychology  
Clinical and Health Psychology, School of Health in Social Science, University of  
Edinburgh, Teviot Place EH8 9AG

**How will the service users be contacted?**

Potential participants will be initially approached (via letter) by a clinician who has worked with them to inform them about and invited them to participate in the study. At this point, they are able to choose to opt-in or not. If they opt-in, they will be asked to provide their contact details to the researcher in order to discuss the project further prior to collecting informed consent.

**How will service users consent be obtained?**

Written informed consent will be collected. This includes consent to:

- Participate in the named study voluntarily
- Record the interview
- Access to medical notes regarding details of the brain injury
- Publish or present the unidentifiable results

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- Review notes and data by sponsor
- Use unidentifiable data in future ethically approved studies
- Store/archive unidentifiable data within the University of Edinburgh for research governance purposes

Additional consent may be collected for: unidentifiable data to be used to develop a patient leaflet.

**If no consent being obtained, please detail the reason why not?**

n/a

**Where will the data be stored?**

The paper recorded data and audio recording devices (x2) will be stored in a locked cabinet within the Department of Neuropsychology, Ashgrove House, Forresterhill Aberdeen AB25 2ZN. Identifiable data (e.g. informed consent forms, recording devices) will be stored separately from the unidentifiable research data (e.g. transcripts).

An unidentifiable electronic database will be stored on the applicant's NHS secure network drive and will also profit from the addition protection of a password. Password protection limits access control (to those mentioned in the current application). Unidentifiable research data will be securely stored on servers within the University of Edinburgh and will be accessible by members of the project team (i.e. Chief investigator and supervisors) and potentially by thesis examiners.

Should there be any further communication of the database between the applicant and supervisors (Dr Maggie Whyte, Dr Emily Newman, Dr Paul Graham Morris), this will remain anonymised/unidentifiable and be transferred electronically (with password protection) via the NHS and University of Edinburgh's secure email server.

**How will the data be protected? (Please detail security measures to be taken)**

As above. The paper recorded data and audio recording devices (x2) will be stored in a locked cabinets located on an NHS secure premises. The recordable devices include encryption and password protection. The audio recordings will only be downloaded onto NHS computers and will be destroyed as soon as they are transcribed.

All electronic data will be unidentifiable and saved on the applicant's NHS secure network drive with password protection. Unidentifiable research data will also be securely stored on servers within the University of Edinburgh and will be accessible by members of the project team (i.e. Chief investigator and supervisors) and potentially by thesis examiners. Only unidentifiable data may be electronically shared between the applicant and supervisors (Dr Maggie Whyte, Dr Emily Newman, Dr Paul Graham Morris) using NHS and University of Edinburgh's secure email server.

All data will be treated on a confidential and need-to-know basis for duration of the project (including access to passwords for electronically shared unidentifiable data).

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Identifiable data will be kept for the limited length of time needed for the project (estimated May 2018) and will undergo appropriate disposal and deletion upon completion, as dictated by local policy and national guidelines.

Unidentifiable research data will be archived within the university for 10 years upon project completion, with a review then and every subsequent 5 years to determine whether data should continue to be retained or whether it should be securely deleted. This is required for research governance purposes (e.g. for checks or clarifications by government or other appropriate organisations) and the consent form specifically requests consent to store this unidentifiable data for these purposes.

**If the data is on a computer is there access via a network?**

The unidentifiable database will be stored securely on the applicant's individual NHS secure network drive and securely stored on servers within the University of Edinburgh for duration of the project. Access to the drive individual NHS secure network drive is limited to the applicant's user login-in and password. Access to University of Edinburgh secure server will be limited to the project team (i.e. Chief investigator and supervisors) and potentially by thesis examiners. Access to this will be further limited as access will also require an unique password.

**How long will the data be stored?**

Audio recordings will only be downloaded onto NHS computers and will be destroyed as soon as they are transcribed. Identifiable paper recorded data will be stored until completion for this project which is estimated for May 2018. Unidentifiable research data will be archived within the university for 10 years upon project completion (for research governance purposes), with a review then and every subsequent 5 years to determine whether data should continue to be retained or whether it should be securely deleted. Specific informed written consent is also collected for this purpose.

**At the end of this period, how will the data be disposed of?**

All data will be disposed in line with local policy and national guidelines. Both audio recordings and paper recorded data will be treated as confidential waste and destroyed in line with trust policy and procedures. Unidentifiable electronic data stored on the applicant's individual NHS secure network drive will be permanently deleted from the applicant's NHS account using the appropriate software (assisted by the Department of eHealth support team - extension 54444) upon completion of the project.

**Who will be responsible for ensuring that the data is disposed of in a confidential manner?**

Applicant: Nicole Chadwick, Trainee Clinical Psychologist  
Supervisor: Dr Maggie Whyte, Consultant Clinical Psychologist

***Please refer to the last page for the six Caldicott Principles before answering the questions below.***

**Q.1 What is the purpose for which data are to be used? (Principle 1)**

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A head injury can not only directly influence an individual, but may also have wider and profound consequences for those around them. Partners are reported to experience high stress levels, and divorce rates are reported to be as high as 54%. Few studies have explored factors that influence couples' relationships from both perspectives after a head injury and little is known about the experiences of individuals and their partners. This is important as these factors may influence an individual's recovery.

The current study will aim to look at couples' experiences after a head injury.

**Q.2 Why is it necessary to use identifiable data? (Principle 2)**

Where possible, all personal identifiable information will be removed from the final dataset. The dataset will include some basic demographic information (e.g. Age, Gender, Employment status, Relationship status, etc) and basic injury specific information (e.g. type of injury and time since injury). It is highly unlikely that any single individual could be identified based on this limited demographic information, however we recognise that there is low.

We recognise that there may be a moderate probability risk of identification from the audio recordings, however these will be encrypted and password protected and will be destroyed upon completion of the unidentifiable transcripts. Interview methodology is crucial to the project as it provides unique information about couple's experiences follow a brain injury. Due to the nature of the analysis being used in the project (Framework analysis) the emphasis will be on general themes found within the sample, rather than focusing on any single individual's experiences, which further supports unidentification. Participants will also be able to express any concerns that they might have about identification or use of unidentifiable quotes in the final results during the respondent validation phase.

**Q.3 Justify the use of each patient-identifiable data field (Principle 3)**

As above,

**Q.4 Who will have access to patient-identifiable information and what control will there be? (Principle 4)**

All data will be treated as confidential and on a need-to-know basis with

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limited access controls. Access to person identifiable information will be limited to the applicant (Nicole Chadwick) and clinical supervisor (Dr Maggie Whyte), which will be locked away and stored securely and separately from the unidentifiable data within the secure premise of the Department of Neuropsychology, Ashgrove House, Forresterhill Aberdeen AB25 2ZN. All other parties mentioned in this application will only have access to unidentifiable data. The unidentifiable electronic database will be stored securely on the applicant's individual NHS and University of Edinburgh secure network drive for duration of the project. Consent is also gained for unidentifiable research data to be archived within the university for research governance purposes for 10 years upon project completion.

**Q.5 Outline actions taken to ensure individuals with access to patient-identifiable information are aware of their responsibilities and obligations to respect patient confidentiality (Principle 5)**

Nicole Chadwick and Dr Maggie Whyte have read the NHS Grampian policy on data protection and confidentiality and have completed all relevant GCP training modules.

**Q.6 Outline the organisational arrangements for complying with legal requirements (Principle 6)**

The project will follow the legal requirements of NHS Grampian and if legal advice is needed this will be sought from the NHS legal department. The project has also gained favourable opinion from North of Scotland (1) Research Ethics Committee.





I confirm that the data will be held and used according to the condition and information given as described with this approval form.

**Applicant:** N. Chadwick

**Job Title:** Trainee Clinical Psychologist

**Signature:** Nicole Chadwick

**Date:** 12.09.17

FOR OFFICE USE ONLY

**Data Protection Act compliant** Yes ☐ No ☐

Comments:

Information Governance Manager: Mr Chris Morrice

Signature ..... Date .....

**Authorisation Granted** Yes ☒ No ☐

Comments:

Caldicott Guardian (NHS Grampian): Dr Nick Fluck, Medical Director, NHS Grampian

Signature ..... Date 15/9/17

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8



**Applicant Notified**

YES NO DATE

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1. The data received from NHS Grampian will be treated as confidential
2. The data received from NHS Grampian will be used only for the purpose(s) described
3. In the case of anonymised or confidential aggregated data, no attempt will be made to identify or contact individuals or organisations identified through this data.
4. The data received from NHS Grampian may be disclosed to staff of the above organisation but only for the described purpose(s)
5. The data received from NHS Grampian may not be disclosed to any third party
6. The data received from NHS Grampian will be stored in secure conditions at all times whether held in electronic medium or as printed hard copies
7. The organisation to which the data is released will maintain and comply with a Data Protection Registration which encompasses the data and data storage usage
8. The data will be destroyed when the work is completed: any printed copies will be destroyed, and files deleted from computer systems (including any copies held on backup or archive media)

All staff given access to data will be made aware of these conditions (Principle 5).

#### **Caldicott Guardian Principles**

**1. Justify the purpose(s)**

Every proposed use or transfer of patient-identifiable information within or from an organisation should be clearly defined and scrutinised, with continuing uses regularly reviewed by an appropriate guardian.

**2. Don't use patient-identifiable information unless it is absolutely necessary.**

Patient-identifiable information items should not be used unless there is no alternative.

**3. Use the minimum necessary patient-identifiable information.**

Where use of patient-identifiable information is considered to be essential, each individual item of information should be justified with the aim of reducing identifiability.

**4. Access to patient-identifiable information should be on a strict need to know basis.**

Only those individuals who need access to patient-identifiable information should have access to it, and they should only have access to the information items that they need to see.

Application Number .....(for office use only)

9

**5. Everyone should be aware of their responsibilities.**

Action should be taken to ensure that those handling patient-identifiable information – both clinical and non-clinical staff – are aware of their responsibilities and obligations to respect patient confidentiality.

**6. Understand and comply with the law**

Every use of patient-identifiable information must be lawful. Someone in each Organisation should be responsible for ensuring that the organisation complies with legal requirements.

Application Number .....(for office use only)

10

**North of Scotland Research Ethics Committee (1)**

Summerfield House  
2 Eday Road  
Aberdeen  
AB15 6RE

Telephone: 01224 558458  
Facsimile: 01224 558609  
Email: nosres@nhs.net



20 February 2018

Miss Nicole Chadwick  
Department of Neuropsychology  
Ashgrove House  
Foresterhill Road  
ABERDEEN  
AB25 2ZN

Dear Miss Chadwick

<b>Study title:</b>	<b>Couples' experiences following a traumatic brain injury (TBI), 12 to 24 months after discharge from inpatient care</b>
<b>REC reference:</b>	<b>17/NS/0091</b>
<b>Amendment number:</b>	<b>1 (Study Ref) AM01 (REC Ref)</b>
<b>Amendment date:</b>	<b>09 February 2018</b>
<b>IRAS project ID:</b>	<b>217488</b>

The above amendment was reviewed by the Sub-Committee in correspondence.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Discussion**

The researchers were contacted by e-mail to reply to queries raised by the Sub-Committee and provided the following clarifications.

The Sub-Committee noted that the:

1. PIS, under the section "Why have we been invited to take part?", still stated "Your clinician has identified that you and your partner may be suitable to take part in this study, as one of you was discharged from inpatient care **in the last year or two** following a traumatic brain injury."
2. Protocol, page 23, para 3 'Beginning the interview', still stated "I know that you [// your partner] were discharged from inpatient care **in the last year or two** following a head injury ...".

The Sub-Committee requested that these statements were changed to reflect "**one to five years ago**".

1

*You were contacted by e-mail to make these corrections and submitted a revised PIS and Protocol to include the requested changes.*

The members of the Sub-Committee reviewed the revised documents and were content to issue a Favourable Opinion.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	1	09 February 2018
Copies of advertisement materials for research participants [Poster Invitation Letter]	1	09 February 2018
Notice of Substantial Amendment (non-CTIMP)	1 (Study Ref) AM01 (REC Ref)	09 February 2018
Other [Cons Referrers Information Sheet]	2	09 February 2018
Participant consent form	2	09 February 2018
Participant information sheet (PIS)	2	09 February 2018
Research protocol or project proposal	2	09 February 2018

#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

#### **Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>17/NS/0091:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



pp'd on behalf of  
**Mrs Sophie Welch**  
Vice-Chair

Enclosures: List of names and professions of members who took part in the review

Copy to: Miss Charlotte Smith, University of Edinburgh  
NHSG R&D Department

**North of Scotland Research Ethics Committee (1)**

**Attendance at Sub-Committee of the REC Meeting by correspondence**

**Committee Members:**

Name	Profession	Present	Notes
Miss Valeria Melis	Research Fellow	Yes	
Mrs Sophie Welch	Vice-Chair & Coach Practitioner	Yes	(Chair)

**Also in attendance:**

Name	Position (or reason for attending)
Ms Sarah Lorick	Assistant Ethics Co-ordinator

**North of Scotland Research Ethics Committee (1)**

Summerfield House  
2 Eday Road  
Aberdeen  
AB15 6RE

Telephone: 01224 558458  
Facsimile: 01224 558609  
Email: nosres@nhs.net



20 February 2018

Miss Nicole Chadwick  
Department of Neuropsychology  
Ashgrove House  
Foresterhill Road  
ABERDEEN  
AB25 2ZN

Dear Miss Chadwick

<b>Study title:</b>	<b>Couples' experiences following a traumatic brain injury (TBI), 12 to 24 months after discharge from inpatient care</b>
<b>REC reference:</b>	<b>17/NS/0091</b>
<b>Amendment number:</b>	<b>1 (Study Ref) AM01 (REC Ref)</b>
<b>Amendment date:</b>	<b>09 February 2018</b>
<b>IRAS project ID:</b>	<b>217488</b>

The above amendment was reviewed by the Sub-Committee in correspondence.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Discussion**

The researchers were contacted by e-mail to reply to queries raised by the Sub-Committee and provided the following clarifications.

The Sub-Committee noted that the:

1. PIS, under the section "Why have we been invited to take part?", still stated "Your clinician has identified that you and your partner may be suitable to take part in this study, as one of you was discharged from inpatient care **in the last year or two** following a traumatic brain injury."
2. Protocol, page 23, para 3 'Beginning the interview', still stated "I know that you [// your partner] were discharged from inpatient care **in the last year or two** following a head injury ...".

The Sub-Committee requested that these statements were changed to reflect "**one to five years ago**".

1



*You were contacted by e-mail to make these corrections and submitted a revised PIS and Protocol to include the requested changes.*

The members of the Sub-Committee reviewed the revised documents and were content to issue a Favourable Opinion.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
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Notice of Substantial Amendment (non-CTIMP)	1 (Study Ref) AM01 (REC Ref)	09 February 2018
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Participant information sheet (PIS)	2	09 February 2018
Research protocol or project proposal	2	09 February 2018

#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

#### **Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>17/NS/0091:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



pp'd on behalf of  
**Mrs Sophie Welch**  
Vice-Chair

Enclosures: List of names and professions of members who took part in the review

Copy to: Miss Charlotte Smith, University of Edinburgh  
NHSG R&D Department

**North of Scotland Research Ethics Committee (1)**

**Attendance at Sub-Committee of the REC Meeting by correspondence**

**Committee Members:**

Name	Profession	Present	Notes
Miss Valeria Melis	Research Fellow	Yes	
Mrs Sophie Welch	Vice-Chair & Coach Practitioner	Yes	(Chair)

**Also in attendance:**

Name	Position (or reason for attending)
Ms Sarah Lorick	Assistant Ethics Co-ordinator

## Appendix 5. Participant information poster

**NHS**  
Grampian

**THE UNIVERSITY**  
EDINBURGH

***What is this study about?***

This study aims to explore couples' relationships and experiences after a head injury.

***Who are we looking for?***

We are looking for couples who may be able to offer their unique experiences to the study. We are looking for couples where one person in the relationship has experienced a head injury and has been discharged from an inpatient service and has been living at home for at least one year to five years. Participation in this study is voluntary and you are able to withdraw at any time.

***What would taking part involve?***

If you and partner agree to take part, you will each be invited to be interviewed separately. Interviews will last from 45 to 90 minutes. You will be asked about your relationship and your experiences since the head injury. All information collected will be kept confidential.

***Who has sponsored and funded the study?***

This study is funded and sponsored by the University of Edinburgh, and has gained ethical approval from the North of Scotland (1) Research Ethics Committee.

***How will the information be used?***

The information collected will be anonymised and made unidentifiable (e.g. names, personal dates, places will be removed or altered) and the unidentifiable findings will be used as part of a doctoral thesis with the possibility to contribute towards a publication in a scientific journal, patient information leaflet and may also help to direct future research.





***How can I get in touch?***

If you are interested, please contact: Nicole Chadwick,  
Researcher/Trainee Clinical Psychologist  
tel: 01224 559352, email: [Nicole.Chadwick@nhs.net](mailto:Nicole.Chadwick@nhs.net)

**couples' experiences**  
**following a traumatic brain injury**

Centre Number: 2017NU005      Study Number: 217488 (17/NS/0091)      Name of Researcher: Nicole Chadwick      version 1.0 (09.02.18)

## Appendix 6. Participant information sheet

 		Title: Couples experiences after a traumatic brain injury	
<h1>couples' experiences following a traumatic brain injury</h1>			
		<h3>INFORMATION ABOUT THE STUDY</h3> <p>We would like to invite you and your partner to take part in a study looking at couples' experiences following a brain injury after they have been discharged from inpatient care.</p> <p>Before you decide if you would like to take part, please take your time to read and think about the following information.</p>	
<h3>What is the purpose of the study?</h3> <p>As clinicians, we understand that a brain injury can have a wide range of effects on people and those around them. This can affect family members in different ways and research has shown that partners can find it very stressful. Most of the research has looked at people's experiences from either the partner's view or the person with the brain injury's view; few studies have asked both the individual and their partner together and little is known about their collective experiences. This is important as these factors may influence recovery. This study aims to explore couples' experiences and relationships after a traumatic brain injury. The aim of the study is not to provide therapy or treatment.</p>		<h3>Why have we been invited to take part?</h3> <p>You have been invited as you have expressed interest in the study after seeing a poster for the study or your clinician has identified that you and your partner may be suitable to take part in this study, as one of you was discharged from inpatient care one to five years ago following a traumatic brain injury. It was felt that together you may be able to offer your unique perspectives and experiences to this study.</p> <p>We are currently looking for people who meet these criteria:</p> <ul style="list-style-type: none"><li>➤ Over 18 years old</li><li>➤ Couples who live together (both married and non-married)</li><li>➤ One of you has sustained a traumatic brain injury and were discharged from inpatient care <b>one to five years ago</b></li></ul>	
Centre Number: 2017NU005		Study Number: 217488 (17/NS/0091)	
Name of Researcher: Nicole Chadwick		version 2.0 (09.02.18)   page 1 of 4	

### What would taking part involve?

After reading this information and if you are interested in taking part, the study will involve:

- If you would like to, you and your partner will be offered a chance to discuss the aims and procedure of the study with a researcher. You can discuss any questions or concerns you might have about taking part.
- If interested, both you and your partner will be asked to sign consent forms to show that you have both read and understood the information provided and agree to participate.
- If you both agree to take part and are suitable for the study, you will be contacted by a researcher to arrange to meet individually for a face-to-face interview at a local clinic at a time convenient for you.
- During the interview, you will be asked about your relationship and your experiences since the brain injury. You don't have to answer every question or speak about anything you wish to be kept private. You can finish the interview or request a break at any time.
- Each interview should last around 45 to 90 minutes and will be recorded using two audio recording devices. The researcher may take some field notes during the interview.
- After, the audio recordings will be made unidentifiable, written up and briefly analysed.
- You will be contacted and offered another one-to-one session to discuss the initial findings with the researcher. You may be able to use the opportunity to make further comments.

### Do we have to take part?

No, you do not have to take part in the study. Whether you chose to participate or not, this will not influence your rights or standard of care you or your partner can receive.

### If we give consent to take part, will we definitely be interviewed?

We want you to know that we appreciate all interest in this study, but will not be able to invite everyone who is interested and consents to take part to interview. Unfortunately, if you have not been contacted within three months after you have expressed interest in the study, you have not been selected and any information you have provided prior to this will be destroyed.

### What if one of us wants to take part but the other does not?

Unfortunately, you will not be able to take part. We want both people in the relationship to feel that they are free to choose to take part or not. If you have any questions about this, feel free to discuss it with the principal researcher.

### Is it possible to withdraw, and how?

Yes. If you chose to participate and decide, at any point, that you wish to withdraw, you can without having to give a reason. To do this, let the researcher know you wish to withdraw or you can complete and return the 'Right to withdraw' form. This also will not affect your rights or the standard of care you or your partner receives. All person identifiable and non-anonymised data will be withdrawn from the study and destroyed.

#### What will happen to the information we share?

Your person identifiable information will be kept confidential, which means that it will be kept private. To help us do this, we will provide each person taking part with a unique, random, anonymised research number. This will be used for all data collected in the study. This means the information you give us will be kept anonymous.

- Any identifiable information that could be linked to you, will be kept private and separate from the rest of the data. So, for example, we will store your consent form and the unidentifiable data from your interview separately.
- All information collected will be kept safe and locked away in secure premises, including the audio recording devices. Once the information has been typed up from the audio recordings, the recordings will be deleted.
- All electronic information will be unidentifiable, encrypted and password protected. Any information that needs to be shared electronically will also be unidentifiable, encrypted and password protected.
- All information collected is treated on a "need to know basis" and therefore access to your information will be limited to the research team. Sometimes other people (e.g. NHS, the university sponsor) may look at the data for audit or quality reasons.

It is important that you understand that confidential does not mean "secret" and there may be some rare cases where we might need to share this information. This will be when we have concerns about your safety or the safety of others.

If you would like a summary of the final results, these can be provided in a written format, discussed via telephone or face-to-face.

#### How will quotes be kept confidential in the final findings?

Quotes will be used, however these (like all other data) will also be made unidentifiable (e.g. names, personal dates, places removed or altered). Quotes that can be linked back to any single individuals will not be used in the study. All participants will also be offered the opportunity to discuss any concerns around this.

#### After the study, what will happen to the information we share?

- The unidentifiable finding of the study will be used as part of a doctoral thesis in Clinical Psychology. It is also hoped that the results will be used to contribute towards a publication in a scientific journal.
- If you consent, unidentifiable information may also be used to develop a patient information leaflet to help future Service Users.
- Anonymised, unidentifiable data will be stored by university for quality and research governance purposes.

#### Who has sponsored and funded the study?

This study has been sponsored, funded and ethically reviewed by the University of Edinburgh. It has also been reviewed and received favourable approval from the North of Scotland (1) Research Ethics Committee, an independent group of people who ensure studies protect individual's rights, safety, wellbeing and dignity.



Title: Couples experiences after a traumatic brain injury

#### What are the possible advantages of taking part?

There may not be direct benefits for you or your partner, however this study may give you the opportunity to share your experiences. In addition, the findings may be shared on a wide scale if the study is successfully published in a peer reviewed journal. If you consent, unidentifiable information or quotes may be used to develop a Service User leaflet.

#### What are the possible disadvantages and risks of taking part?

Some people may find the sensitive nature of the questions difficult to discuss, however you can request a break or to stop at point. Similarly, if you feel tired or fatigued during the interview, you can have a break or to stop at point.

If either of you lose the capacity or ability to consent at any point in the study, the interview will be discontinued and your information would be withdrawn from the final findings.

This study will not aim to provide therapy or treatment, however if there are concerns about your wellbeing, the researcher can advise you around ways to access a range of local supports.

#### Who do I contact if I have any questions?

If you would like to contact a member of the research team about the study, please contact:

**Nicole Chadwick**, Principal researcher/Trainee Clinical Psychologist  
tel: 01224 559352

**Dr Emily Newman**, Health Psychology Lecturer/Research Director in Clinical Psychology and Postgraduate Research Director in Clinical Psychology

email:  
Nicole.Chadwick@nhs.net

tel: 0131 651 3945

email:  
Emily.Newman@ed.ac.uk

**Dr Maggie Whyte**, Consultant Clinical Neuropsychologist

tel: 01224 559352

email: maggiewhyte@nhs.net

**Dr Paul Graham Morris**, Lecturer in Health Psychology

tel: 0131 651 3956

email: P.G.Morris@ed.ac.uk

If you would like to seek independent advice about taking part in this study, you can contact:

Dr Angus MacBeth, Lecturer in Clinical Psychology

Department of Clinical and Health Psychology, School of Health in Social Science, The University of Edinburgh, Teviot Place, Edinburgh EH8 9AG

tel: 0131 650 3893

email: angus.macbeth@ed.ac.uk

#### Who do I contact if I have any concerns?

If you have any concerns or complaints about anything to do with this study, then you can contact:

Edinburgh University Research Governance Team

email: [resgov@accord.scot](mailto:resgov@accord.scot)

**Thank you taking time to read this information sheet.**

**Do let us know if you have any questions.**

Centre Number: 2017NU005





Study Number: 217488 (17/NS/0091)

Name of Researcher: Nicole Chadwick

version 2.0 (09.02.18) | page 4 of 4



## Appendix 7. Consultation information sheet

 	Title: Couples experiences after a traumatic brain injury
<p>couples' experiences following a traumatic brain injury</p>	
	<p><b>INFORMATION FOR PEOPLE WHO MAY CONSULT ON THE PROJECT</b></p>
<p>Before you decide if you would like to take part, please take your time to read and think about the following information.</p>	
<p><b>What is the purpose of the study?</b></p>	
<p>As clinicians, we understand that a head injury can have a wide range of effects on people and those around them. This can affect family members in different ways and research has shown that partners can find it more stressful than parents. Most of the research has looked at people's experiences from either the partner's view or the person with the head injury's view; few studies have asked both the individual and their partner together and little is known about their collective experiences. This is important as these factors may influence recovery. This study aims to tap into and explore these experiences. The aim of the study is not to provide therapy or treatment.</p>	
<p><b>Why have I been invited to take part?</b></p>	
<p>You are a responsible clinician or neuropsychologist in NHS Grampian who works with clients who have experienced a traumatic brain injury.</p>	
<p><b>What would my responsibilities be?</b></p>	
<p>Participation is <u>voluntary</u>.</p>	
<p>If you chose to participate, we will ask you:</p>	
<ul style="list-style-type: none"><li>➤ To identify patients in your care, who you feel meet the study referral criteria.</li><li>➤ To write to the potential patient and send them an invitation letter about the study and opt-in letter.</li><li>➤ To be available in the first instance to answer any question that they might have or signpost them to the researcher to answer their questions or for further information.</li></ul>	
Centre Number: 2017NU005	Study Number: 217488 (17/NS/0091)
Name of Researcher: Nicole Chadwick	version 2.0 (09.02.18)   page 1 of 4

#### Inclusion criteria

- 18 years or greater
- Involvement in a cohabiting marital or non-marital relationship pre- and post-injury
- A diagnosis of traumatic brain injury in the one partner of the dyad
- Those who have been discharged from inpatient care in the last **year to five years**
- Ability to give informed consent
- Ability to understand and communicate verbally in English to a satisfactory level for participation in an interview

#### Exclusion criteria

- Individuals who lack capacity to provide informed consent and/or those who are unable to participate in the interview process

#### How long will I be expected to identify and make referrals?

The study aims to recruitment participants from **August 2017 to April 2018**. The overall project aims to be completed for thesis submission in May 2018.

#### What will happen to patients that I refer?

- If potential participants choose to opt-in, they will be sent two consent forms, a brief survey and will be contacted by the researcher to discuss the project further and answer any questions.
- If they consent to participate, they will be contacted individually to arrange a time that suits them to meet for an interview.

- In the interview, they will be asked about their relationship and their experiences since the traumatic brain injury. This will last between 45 to 90 minutes and will be recorded using two audio recording devices.
- After the interview, the audio recordings will be transcribed and made unidentifiable. This will be initially analysed using Framework Analysis.
- Participants will be offered another meeting to discuss the initial findings (respondent validation).
- All participants will be offered a summary of the final findings (via writing, telephone or face-to-face).

#### Will I be informed of my patient's progress?

No, not directly; however you can request an anonymised, unidentifiable summary of the overall findings.

#### What are the responsibilities of the researchers?

If you chose to participate, you can expect the research team to:

- Be available to answer any questions or concerns you, your patients or their partners have about the study.
- To invite and seek informed consent from potential participants.
- To interview all participants.
- To analyse the data and disseminate the findings.
- To manage confidentiality and risk in line with relevant legislation, policies and procedures; and signpost participants to local supports when necessary.

#### What are the possible advantages and disadvantages for my patients?

There may not be direct benefits for the patient or their partner, however this study may give them the opportunity to share their experiences.

Some participants may find the sensitive nature of the questions difficult to discuss, however breaks and the opportunity to stop will be made available to them. This study will not aim to provide therapy or treatment, however if there are concerns about their wellbeing, the researcher will be able to advise them on a range of local supports.

#### What are the possible advantages and disadvantages for me?

There are few direct advantages and disadvantages for consultants volunteering in this project. Consultants may feel that they can benefit from indirectly contributing to research, particularly as it is hoped that the project will seek to gain publication in a peer reviewed journal. The anonymised results of the project can also be requested.

With regards to possible disadvantages, time, understandably, may act as a constraint (such as time to identify potential participants and write to participants).

#### Who has sponsored and funded the study?

This study has been sponsored, funded and ethically reviewed by the University of Edinburgh. It has also been reviewed and received favourable approval from the North of Scotland (1) Research Ethics Committee.

#### Who do I contact if I have any questions?

If you would like to contact a member of the research team about the study, please contact:

**Nicole Chadwick**, Principal researcher/Trainee Clinical Psychologist  
tel: 01224 559352  
email: Nicole.Chadwick@nhs.net

**Dr Emily Newman**, Health Psychology Lecturer/Research Director in Clinical Psychology and Postgraduate Research Director in Clinical Psychology  
tel: 0131 651 3945  
email: Emily.Newman@ed.ac.uk

**Dr Maggie Whyte**, Consultant Clinical Neuropsychologist  
tel: 01224 559352  
email: maggiwhyte@nhs.net

**Dr Paul Graham Morris**, Lecturer in Health Psychology  
tel: 0131 651 3956  
email: P.G.Morris@ed.ac.uk

If you would like to seek independent advice about taking part in this study, you can contact:

**Dr Angus MacBeth**, Lecturer in Clinical Psychology  
Department of Clinical and Health Psychology, School of Health in Social Science, The University of Edinburgh, Teviot Place, Edinburgh EH8 9AG  
tel: 0131 650 3893  
email: angus.macbeth@ed.ac.uk



Title: Couples experiences after a traumatic brain injury

**Who do I contact if I have any concerns?**

If you have any concerns or complaints about anything to do with this study, then you can contact:

Edinburgh University Research Governance Team

email: [resgov@accord.scot](mailto:resgov@accord.scot)

**Thank you taking time to read the consultant information sheet.**

**Do let us know if you have any questions.**

## Appendix 8. Sample invitation letter

NHS Grampian

Department of Neuropsychology  
2<sup>nd</sup> Floor  
Ashgrove House  
Aberdeen Royal Infirmary  
Foresterhill  
Aberdeen  
AB25 2ZN  
Secretary 01224-559352



Dear Sir / Madam,

**RE: Research Study - Couples' experiences after a traumatic brain injury**

I am writing to you and your partner as you expressed interest a research study around couples' experiences after a traumatic brain injury. There has been little research collectively exploring both individuals' experiences and, therefore, it would be helpful to gain information about your experiences after head injury.

To help you to learn more about the study, we have enclosed a more detailed information sheet to look over at your own pace. Please feel free to discuss the details of the study with your family and friends whilst considering whether to participate.

If this has interested you, you may contact the researcher on the number below or return the 'Consent to contact' slip in the enclosed prepaid envelope. Participation is entirely voluntary.

If I do not hear from you within a month of the receipt of this letter, I will assume that you do not wish to take part.

Thank you for your time.

Yours sincerely,

Centre Number: 2017NU005  
Name of Researcher: Nicole Chadwick

Study Number: 217488 (17/NS/0091)  
version 1.0 (09.02.18) | page 1 of 2

**Consent to be contacted by telephone** (Service User)

I agree to receive a telephone call to find out more information regarding the research study  
"Couples' experiences after a traumatic brain injury".

Name (please print): \_\_\_\_\_

Contact number: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

If interested or possibly interested, please contact the researcher on the number below or return this Consent to contact slip to the below address using the prepaid envelope enclosed. If you are not interested/do not wish to participate in the current study, then there is no need to reply.

Nicole Chadwick, Trainee Clinical Psychologist/Principal researcher  
Neuropsychology department, Ashgrove House, Foresterhill Road, Aberdeen AB25 2ZN  
tel: 01224-559352

-----  
**Consent to be contacted by telephone** (Partner)

I agree to receive a telephone call to find out more information regarding the research study  
"Couples' experiences after a traumatic brain injury".

Partner Name (please print): \_\_\_\_\_

Contact number: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_



If interested or possibly interested, please contact the researcher on the number below or return this Consent to contact slip to the below address using the prepaid envelope enclosed. If you are not interested/do not wish to participate in the current study, then there is no need to reply.

Nicole Chadwick, Trainee Clinical Psychologist/Principal researcher  
Neuropsychology department, Ashgrove House, Foresterhill Road, Aberdeen AB25 2ZN  
tel: 01224-559352

Centre Number: 2017NU005  
Name of Researcher: Nicole Chadwick

Study Number: 217488 (17/NS/0091)  
version 1.0 (09.02.18) | page 2 of 2

## Appendix 9. Consent forms (blank)

 	<p>Title: Couples experiences after a traumatic brain injury</p>	<p>Participant Number:</p>
<p><b>Consent form - Service User</b></p>		
<p><b>Please <u>initial</u> each box to indicate your agreement to the following statements:</b></p>		
I have read and understood the information sheet for the above study (v2, 09.02.18).	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsor(s) (NHS Lothian and the University of Edinburgh) or from the/other NHS Board(s) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records.
I have had the opportunity to think about the information, ask questions and have had these answered to my satisfaction.	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>	I agree to my unidentifiable data being used in future ethically approved studies.
I understand that taking part in this study is voluntary and that I am free to withdraw from the study at any time (without giving a reason).	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>	I understand that unidentifiable data will be archived within the University of Edinburgh for research governance purposes.
I understand that the study is for the purpose of research and not for treatment.	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>	I agree to take part in the above study.
I give permission for the interview to be audio recorded.	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>	
I give permission for the principal researcher (Nicole Chadwick, Trainee Clinical Psychologist) to have access to my medical notes regarding the details of my head injury.	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>	
I give permission and understand that if the results of this study are presented or published, the data will be made unidentifiable.	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>	

PARTICIPANT	PERSON TAKING CONSENT
Name	Name
Signature	Signature
Date	Date

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

Centre Number: 2017NU005	Study Number: 217488 (17/NS/0091)	Name of Researcher: Nicole Chadwick
		version 2.0 (09.02.18)   page 1 of 1

**Consent form - Partner**

Please initial each box to indicate your agreement to the following statements:

I have read and understood the information sheet for the above study (v2, 09.02.18).

☐

I have had the opportunity to think about the information, ask questions and have had these answered to my satisfaction.

☐

I understand that taking part in this study is voluntary and that I am free to withdraw from the study at any time (without giving a reason).

☐

I understand that the study is for the purpose of research and not for treatment.

☐

I give permission for the interview to be audio recorded.

☐

I give permission and understand that if the results of this study are presented or published, the data will be made unidentifiable.

☐

I understand that relevant sections of my data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsor(s) (NHS Lothian and the University of Edinburgh) or from the/other NHS Board(s) where it is relevant to my taking part in

☐

this research. I give permission for those individuals to have access to my records.

I agree to my unidentifiable data being used in future ethically approved studies

☐

I understand that unidentifiable data will be archived within the University of Edinburgh for research governance purposes.

☐

I agree to take part in the above study.

☐

PARTICIPANT	PERSON TAKING CONSENT
Name	Name
Signature	Signature
Date	Date

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.



## Appendix 10. Relationship (screening) survey and Demographics form



Title: Couples experiences after a traumatic brain injury

Participant Number:



### Screening information

Please complete the following as best you can. Don't worry if you are unsure of exact dates.

#### Relationship information

1. Length of relationship with partner

\_\_\_\_\_ years

\_\_\_\_\_ months

2. Marital status

☐

Married

☐

Co-habiting

☐

Separated

☐

Divorced

3. Has this changed since the head injury?

☐

Yes

☐

No

if yes, please specify: \_\_\_\_\_

4. Were you living with your partner at the time of the head injury?

☐

Yes

☐

No

5. Are you currently living with your partner?

☐

Yes

☐

No

6. Do you have children (i.e. below the age of 18)

☐

Yes

☐

No

if yes, how many? \_\_\_\_\_

Please hand back the form to the researcher when completed.  
Thank you.

Centre Number:

Name of Researcher: Nicole Chadwick

Study Number: 217488

v1.0 | 1

Patient form

Please complete the following as best you can. Don't worry if you are unsure of exact dates.

1. Gender	<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Other
<hr/>			
2. Age	_____ years		
<hr/>			
3. Nationality	<input type="checkbox"/> British (UK)	<input type="checkbox"/> EU	<input type="checkbox"/> Other
<hr/>			
4. Highest education qualification	<input type="checkbox"/> None	<input type="checkbox"/> CSE/GCSE D-G	
	<input type="checkbox"/> O-Level/GCSE A-C	<input type="checkbox"/> A-Level	
	<input type="checkbox"/> Higher education, below degree	<input type="checkbox"/> Degree	
<hr/>			
5. Employment status	<input type="checkbox"/> Self-employed	<input type="checkbox"/> Employed	
	<input type="checkbox"/> Retired	<input type="checkbox"/> Unemployed	
<hr/>			
6. Has this changed since the injury?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
if yes, please specify: _____			
<hr/>			
7. Previous/current occupation	please specify: _____		
<hr/>			

Please hand back the form to the researcher when completed.  
Thank you.

Centre Number:  
Name of Researcher: Nicole Chadwick

Study Number: 217488  
v1.0 | 1

**Partner form**

Please complete the following as best you can. Don't worry if you are unsure of exact dates.





1. Gender	<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Other
2. Age	_____ years		
3. Nationality	<input type="checkbox"/> British (UK)	<input type="checkbox"/> EU	<input type="checkbox"/> Other
4. Highest education qualification	<input type="checkbox"/> None	<input type="checkbox"/> CSE/GCSE D-G	
	<input type="checkbox"/> O-Level/GCSE A-C	<input type="checkbox"/> A-Level	
	<input type="checkbox"/> Higher education, below degree	<input type="checkbox"/> Degree	
5. Employment status	<input type="checkbox"/> Self-employed	<input type="checkbox"/> Employed	
	<input type="checkbox"/> Retired	<input type="checkbox"/> Unemployed	
6. Has this changed since the injury?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
	if yes, please specify: _____		
7. Previous/current occupation	please specify: _____		

Please hand back the form to the researcher when completed.  
Thank you.

Centre Number:  
Name of Researcher: Nicole Chadwick

Study Number: 217488  
v1.0 | 2

## Appendix 11. Participant debrief and contact sheet

		Title: Couples experiences after a traumatic brain injury	Participant Number:
<p>couples' experiences following a traumatic brain injury</p>			<b>How can I contact the research team?</b>
		<b>DEBRIEF</b>	If you would like to contact a member of the research team, please contact:
Thank you for taking part and sharing your experiences.		<b>Nicole Chadwick</b> , Principal researcher/Trainee Clinical Psychologist tel: 01224 552699 email: Nicole.Chadwick@nhs.net	<b>Dr Emily Newman</b> , Health Psychology Lecturer/Research Director in Clinical Psychology and Postgraduate Research Director in Clinical Psychology tel: 0131 651 3945 email: Emily.Newman@ed.ac.uk
We really value your time and contribution.		<b>Dr Maggie Whyte</b> , Consultant Clinical Neuropsychologist tel: 01224 552699 email: maggiwhyte@nhs.net	<b>Dr Paul Graham Morris</b> , Lecturer in Health Psychology tel: 0131 651 3956 email: P.G.Morris@ed.ac.uk
If you would like to seek independent advice about taking part in this study, you can contact:		<b>Dr Angus MacBeth</b> , Lecturer in Clinical Psychology Department of Clinical and Health Psychology, School of Health in Social Science, The University of Edinburgh, Teviot Place, Edinburgh EH8 9AG tel: 0131 650 3893 email: angus.macbeth@ed.ac.uk	
Centre Number:	Study Number:	Name of Researcher: Nicole Chadwick	version 1.0 (12.07.2017)   page 1 of 2

#### Local supports

If you would like advice, information or support, there are a number of different contacts, including:

- **The Brain Injury Grampian group (BIG)** is a volunteer-led charity aiming to support all people in Grampian affected by Acquired Brain Injury (ABI) raising awareness of the condition and reducing the social isolation often experienced by people affected by ABI.  
<http://brain-injury-grampian.weebly.com/>  
 tel: 07532186155  
 email: [info.bigggroup@gmail.com](mailto:info.bigggroup@gmail.com)
- **Headway** is a national charity which provides information and support to people with brain injury and their carers.  
<https://www.headway.org.uk/>

These are independent organisations with no connection to the research project.

#### Who do I contact if I have any concerns?

If you have any concerns or complaints about anything to do with this study, then you can contact:

Edinburgh University Research Governance Team  
 email: [resgov@accord.scot](mailto:resgov@accord.scot)

## Appendix 12. Interview schedule

The interview process will take a semi-structured format.

Materials required:

- Dictaphones (x2)
- Consent forms (x2)
- Demographic screening questionnaire
- Debrief handout
- Field notes

### 1. Arrival<sup>1</sup>

*Aim: Establish a rapport and informally assess willingness/anxiety*

Introductions (e.g. names, explain role)

Neutral, brief discussions, e.g. How was your trip in today?

How have you been since we spoke on the phone? *Probe:* How are you feeling today?

### 2. Introducing the research

*Aim: Provide overview of research, the rationale and purpose. Discuss set up of interview procedure (e.g. confidentiality, use of recording devices, interview length) and establish informed consent.*

It's been \_\_\_\_ week(s) since we last spoke, do you have any further questions since we last spoke and since you've had more time to look over the information sheet?

As you are aware, I am interested in exploring the experiences of couples' following a head injury. I am particularly interest in understanding more about couples' relationships, as there seems to be limited information in the research literature around couples' experiences following a head injury. We invited you and your partner to participate as it was felt that you both may be able to offer your unique perspectives and experiences to this. You will have separate interviews so that you could give your own experiences about your relationship after the head injury.

The interview will be recorded and may last between 45-90 minutes. We can see how we get on today; please do not feel you have to use all of that time as we can have a break or stop at any point. Participation in this study is voluntary and if you wish to, you can withdraw from the study at any point, without giving a reason and with no effect on your treatment as usual.

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<sup>1</sup> General structure adapted from Ritchie and Lewis (2003)

At the end of the interview, you may see me making some field notes; I will do these to help with my memory and for me to write down any general observations. The data from the interview will be transcribed, made unidentifiable and initially analysed. You will be then offered another session to go through these and give any further feedback. Once completed and fully analysed, you will also be offered the chance to have a summary of the final results.

Everything we discuss will be kept confidential, which means private and will not be shared with anyone outside of the research team (as stated in the information sheet). All information collected will also be made unidentifiable to help keep your data confidential, so your data will be assigned a random, anonymised research number and no person identifiable information will be used in the final results. This includes any quotes that we may use in the final findings. The only times where I may have to break confidentiality is if we have concerns around your safety or the safety of others. This is to keep everyone safe.

Do you have any further questions? Are you happy to continue today?

*If yes: request to complete consent forms*

### 3. Beginning the interview

*Aim: Collect contextual information*

I know that you [// your partner] were discharged from inpatient care in the last year or two following a head injury, can you tell me about any consequences you are experiencing due to the head injury at the moment and how that has impacted on your relationship?

### 4. During the interview

*Aim: Explore the key themes*

Definition of relationship

- What do you find important in your relationship? *Probe:* Has this changed since your [// your partner's] head injury? How do you feel about the changes? Have there been any positive changes? Have there been any negative?
- What helps with your relationship? What does not help your relationship? Has this changed since [// your partner's] head injury?

Impact on the individual, Partner & Relationship

- Some people find that they have to make certain adjustments in their relationships after a head injury; for example one's roles or how one communicates within a relationship. Are there any adjustments you have had to make? *Probe:* How have the adjustments affected your relationship? How has it gone making these adjustments (Easy? Difficult?)?

- What roles do you feel you and your partner take in your relationship? Have these changed since your [// your partner's] head injury, positively or negatively?
- Has the way you and your partner talk about your relationship and its challenges changed? *Probe:* Tell me about how the two of you communicate about your relationship.
- Has the way you spend time together changed? *Probe:* Have the activities you like to do together as a couple changed? Has your ability to do things your both enjoy changed since your [// your partner's] head injury?
- Have you noticed any changes within your partner since the head injury and do you feel these have impacted on your relationship? *Probe:* have you noticed any changes in the way your partner perceives, feels or responds to situations? Do you feel your partner treats you differently? Do you feel these have made a difference to you? Would your partner agree with that?
- Have you noticed any changes within yourself since the head injury and have these had any impact on your relationship? *Probe:* have you noticed any changes in the way you perceive, feel, or respond to situations? Do you feel you treat your partner differently? What might your partner say?
- Have you noticed if things have stayed the same or if there have been any changes in your physical intimacy and ability to be intimate since your [// your partner's] head injury? *Probe:* How might have these changed? What has influenced this? How does this make you feel?
- Some people say feeling committed and being able to relate to each other is important in a relationship. Some do not. What's your opinion? *Probe:* How do you relate to each other as a couple? Do you feel you are committed or can relate to your partner? Do you feel your partner is (committed or can relate to you)? How do you know this is the case? What would your partner say? Has this changed since your [// your partner's] head injury?

#### Treatment and support

- What advice would you give other couples who have experienced a head injury regarding their relationships? *Probe:* What would you suggest helps? What would you suggest does not help?
- Thinking generally, is there anything you think services could do to help couples relationships? *Probe:* At what point would you find this helpful? At what stage of your rehabilitation?
- Is there anything that you have found services do that has been less helpful to you as a couple?

#### 5. Ending the interview

*Aim: Indicate coming to the end of the interview (5-10 minutes beforehand)*



In the last few minutes, is there anything we have not yet spoken about which you would like to share? *Probe:* Is there anything else you feel may be influencing your relationship (e.g. financial strain, employment, social support and network)?

## 6. After the interview

*Aim: Provide debrief*

Thank you for your contribution. All your data from the interview will be kept private and you will be assigned an anonymised research number that will refer to your collect data which will also be made unidentifiable. This will be transcribed and initially analysed by myself to look for general themes. I will then offer you another session to discuss these themes and allow you to add any further information if you would like to.

Do you have any questions? Any concerns?

Provide debrief handout.

Questions adapted from Gill *et al.* (2011) and White and Newman (2016).

### *Additional prompts*

- Why is that?
- What makes you say \_\_\_\_\_?
- People talk a lot about \_\_\_\_\_. Do you see that as being relevant here?
- You've said \_\_\_\_\_, but was there anything that fell short of your expectations?
- Are there other cases where your decision would be different?
- Can you tell me a little more about \_\_\_\_\_?
- Can you give me an example of \_\_\_\_\_?
- When you say \_\_\_\_\_, what gave you that impression?
- How did you respond when...?
- What did you feel when...?
- Why did you think it was important to...?
- What effect did that have on you?
- Did that help you in any way?
- How did your approach change when you found that out?
- What makes you say that?
- Could you just explain what you mean by \_\_\_\_\_?
- You said \_\_\_\_\_. In what way was it \_\_\_\_\_?
- This may sound like an obvious question, but why...?
- I just want to make sure I've really understood you. What was it exactly that...?'
- Can I take you back to something you said earlier...?

## Appendix 13. Framework analysis stage 2: Developing framework

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### **TBI Changes:**

The experiences of symptoms

- Physical/functional ability
- Cognitive
- Insight
- Emotional/behavioural
- Personality
- Identity
- Social functioning
- Impact on the partner
- Other responses to TBI change
- Loss

Recovery

- Time
- Persisting symptoms

### **Relationship dynamics:**

Partnership

- Shared experience/problem
- Shared activities

Communication

Role change

- Financial/employment

Affection and sexual intimacy

- Sexual functioning
- Affection

### **Managing changes:**

Managing changes within the relationship

- Support within the relationship
- Practical support
- Emotional support
- Reciprocal support
- Coping
- Shared coping
- Dependence
- Changing perspective/philosophy
- Changes in priorities

---

#### The role of services

- Acknowledging relationship
- Possible barriers to accessing support
- Formal therapeutic input
- Involvement of partner in rehabilitation
  - In rehab (formal)
  - In rehab (informal)
- Partner (unmet needs)
- Couple (unmet needs)

#### Advice to other couples

#### **Relationship characteristics and other possible mediating factors:**

##### Relationship characteristics

- Pre-injury relationship strength
- Empathy
- Appreciation
- Feeling understood
- Love
- Recognising partner strengths
- Relationship strength and endurance
- Commitment
- Unconditional

##### Other possible mediating factors

- Other mediating factors
- Ageing
- Transitions
- Previous relationship experiences
- Previous ABI knowledge
- Previous difficult experiences
- Spirituality
- Other

#### **Family and social system**

##### Family

- Impact/Response
- Support

##### Social network

- 
- Response
  - Support

**Miscellaneous**

Making comparisons

- Previous, current and desired self
- To others
- Societal norms

Interview process

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**Appendix 14. Framework analysis stage 3: Indexing (Coding sample). Pt = participant, I = interviewer**

Pt	<p>...umm but at the time because I felt I was umm starting to walk... normally quicker than I was, you know... umm medical staff told they wouldn't expect people to, to be able to do that quickly. I felt I was recovering fully quickly and I thought I was ok. But, you know, [partner] tells me now that umm you know, things were not right that she notices, noticed changes in personality that I just wasn't aware of at all because I was focused on the physical side of things not thinking of any change in my personality. So, I think that she had to umm... cope with a bit more than I did because she was having to deal with someone... umm who was different... umm whose perhaps, I hope, signs of recovery but not always aware of this. She was my wife, she wasn't a clinical expert, so she was trying to advice and support me but... the only information that she could get that would support me, because we did a lot of, sort of, thinking and analysis of what had happened. You know, she was only able to look at the internet and get some advice, but be aware of her limitations I think... umm, in doing that. I think she was trying to get me the best support, advice that she could, but dealing with someone that she maybe felt didn't fully understand that all himself and chose how to explain that to me. So, I... I... I guess because the injury... umm... affected me... quite a bit... umm in some ways, I became very, very conscious of the support I was getting from [partner] and her dedication in providing that support. Had we had a weak relationship, she just couldn't have put up with me and it would have broken us... and the fact that we stayed together and I was conscious of getting her support made me umm... feel... much more... confident and happy about our relationship because I thought if someone could really... deal</p>	<p>TBI consequences - physical; recovery – changes over time; insight</p> <p>TBI consequence – personality</p> <p>Impact on partner</p> <p>Insight Support within relationship – general and practical; Coping - external</p> <p>Insight</p> <p>Commitment; Appreciation</p> <p>Relationship strength and endurance; Pre-injury strength</p>
----	---	--

	with all of that and provide that support and help with you and never show really any sign of weakness or doubt umm you know in the relationship umm it say a huge amount about the strength of the relationship. That she could do that.	
I	I'm hearing a lot about the things that make you feel that this relationship is strong and it also, you've mentioned a bit about the changes that you've experienced perhaps that you weren't aware of them at the start. But... it sounds like you are a bit more aware...? How has it effecting things at the moment with you, like in your relationship?	
Pt	Umm... I... I think... umm... in most prospects I feel as though I'm fully recovered. There are some symptoms that I have got that are really just irritations; they're not things that affect my lifestyle. For example, when I'm tired or if I'm under pressure, my speech slurs... my balance is affected. These are the things that, you know, I know are there but I... I can live with them. Umm but in other respects I feel as though I'm over it. So, in terms of how it... that affects our relationship there is nothing there that puts pressure on us as a couple. But I think the confidence that we have come through... umm particularly the first year, one that was... very demanding but... it was that... umm... I don't have the sense... I don't feel... and I don't think [partner] feels that that pressure put our relationship under strain, made us think is it worth maintaining our relationship when it becomes so difficult. I think that it's probably the opposite, it's the fact that... she wanted to help me umm that really made me feel incredibly good at. Makes me love and respect [partner] even more. So, now that the sort of, if you like, the medical... issues are... are... are not very apparent at all. I suppose what we take from it is that we went through something that was challenging and dealt with it as a couple very, very well and I have a huge amount of love	<p>TBI consequences – physical; Recovery – changes over time and persisting symptoms</p> <p>Communication</p> <p>Love; Appreciation; Relationship strength and endurance; Commitment</p> <p>TBI consequence – physical Support within relationship – general Partnership – shared experience and coping</p>

	<p>and respect for [partner] and the way she dealt with me and helped me at that time. Had I not had that, I could have had a very different... difficult... different experience, and the fact I've come through it makes me, you know, feel very good about my marriage and the relationship that... that we've got. It makes me love [partner] even more. Because I see someone whose qualities that I always knew about, but those qualities really helped me at a challenging time and makes me love her all the more because of that. So.</p>	<p>Love; Appreciation</p> <p>Relationship strength and endurance</p> <p>Recognise partner strengths; Love</p>
I	<p>it does sound like... when you're describing it I can see that you are smiling there as well as you are describing it... so, that strength that you spoke about earlier is really coming through. And, I know that you were saying... so... I can... so, we know that you saying about the impact it's had on you and how you felt and what about, say with [partner], when you have been around her, are there certain adjustments that she's needed to make that you've seen and how's that impacted on your relationship?</p>	
Pt	<p>Umm I... umm that's an interesting question as it is something that I've thought about. There are things that I think in every relationship that, you know, you don't get married to someone who is... umm the same as yourself that you find is ideal because they have no faults, everyone has faults, I have faults... some of which are apparent to me and I try to, to do something about. [Partner] has faults as well. But... you know, umm, I think now the fact that she helped me with all of my faults makes me much more forgiving of any faults that I see in her. I don't see these as things that are irritations, things that you know we can deal and if we deal with them it can make our relationship stronger...</p>	<p>Interview process</p> <p>Previous relationship experience</p> <p>Appreciation, Relationship strength and endurance</p>

#### Appendix 15. Framework analysis stage 4: Charting of themes for dyadic analysis across dataset

	T1	T2	T3	T4	T5	Pa	Pb	Pc	Pd	Pe
Interview processes	6	0	3	4	5	1	0	2	0	0
<b>'You begin to realise that, actually, life may not be the same ever [again]...' (P)</b>										
<i>Changes resulting from TBI symptoms on the couple</i>										
Physical	8	4	1	10	6	3	3	5	13	4
Functional	0	2	9	4	5	3	2	3	5	8
Cognitive	1	10	10	15	19	3	4	6	2	8
- Insight	6	5	6	4	5	4	0	4	0	6
Behavioural	2	1	10	2	0	3	0	1	1	16
Emotional	4	11	16	15	2	9	0	19	10	22
Personality	1	0	0	0	0	0	0	2	0	6
- Identity	2	0	2	0	0	2	0	2	0	0
Social functioning	0	2	4	0	1	6	0	7	0	1
Impact on partner	9	6	9	4	1	8	0	1	4	22
Responses to TBI changes	0	0	3	0	1	5	0	4	0	0
Loss	0	0	0	1	0	0	0	7	0	2
<i>Effect of time and TBI recovery on the relationship</i>										
- Time	4	6	14	11	16	13	11	14	8	24
- Persisting symptoms	5	0	0	1	0	0	0	1	1	12
<i>Changes within the couples' relationship Dynamics</i>										
Communication	8	19	13	25	9	18	1	19	9	15



	T1	T2	T3	T4	T5	Pa	Pb	Pc	Pd	Pe
Role change	0	7	4	9	0	9	2	7	3	12
- Financial-employment	2	11	2	4	8	8	1	6	6	9
Reciprocal support	7	4	2	0	0	7	0	4	0	0
Affection and sexual functioning										
- Affection	0	4	0	5	0	0	0	0	5	1
- Sexual functioning	0	2	1	0	0	0	0	2	0	0
Time together (Shared activities)	2	6	3	8	7	6	5	2	9	3
<b>Perceived influences of and influences on relationship endurance following TBI</b>										
<i>Pre-injury factors</i>										
Strong pre-injury relationships	4	0	0	2	0	1	0	1	1	0
Learning from the past										
- Previous ABI knowledge	0	0	0	2	0	0	0	1	1	0
- Previous difficult experiences	0	2	0	0	0	0	0	0	0	0
- Previous relationship experiences	6	0	0	0	0	0	0	1	0	0
Having faith	0	0	0	0	7	0	10	0	0	0
<i>Within relationship post-injury processes</i>										
Relationship strength post-injury	12	4	2	4	2	0	1	3	0	5
Appreciation	14	6	4	0	2	0	0	1	0	0
- Recognising partner strengths	4	1	5	0	1	0	0	6	0	0
Feeling understood	4	1	0	2	6	5	1	1	5	0
Empathy	3	0	0	0	0	0	0	0	4	0
Love	4	1	0	0	1	0	1	0	0	0
Commitment	10	3	1	1	4	4	1	2	0	0
Unconditional	3	0	0	0	0	0	0	0	0	0
Partnership	1	0	0	0	0	0	0	0	0	0

	T1	T2	T3	T4	T5	Pa	Pb	Pc	Pd	Pe
- Shared coping	10	0	1	0	0	2	3	0	1	4
- Shared experience	5	2	2	0	1	2	0	0	0	0
- Shared problem	0	0	0	0	0	0	0	0	0	0
<i>Within relationship support and coping post-injury</i>										
Coping strategies	0	1	0	0	0	0	0	3	0	0
- External	1	0	0	0	0	0	0	1	0	2
- Internal	0	1	1	0	0	2	1	3	0	16
• Expectations	0	2	1	2	0	3	0	0	6	2
• Perspective-philosophy	1	2	0	0	12	1	3	2	0	1
• Survivor	0	0	0	0	0	0	0	1	0	2
• Priorities	1	0	0	0	0	0	1	0	0	1
• Comparisons	0	0	0	0	0	0	0	0	0	2
▪ Old, new, desired self	0	0	1	1	0	0	0	9	1	4
▪ Others	1	1	0	0	1	5	0	4	3	11
▪ Societal norms	0	0	0	0	0	1	1	0	0	2
Support within the relationship	0	0	0	0	0	0	0	0	0	0
- Dependence	1	4	8	0	0	4	0	0	0	0
- Emotional	8	0	0	0	2	1	0	2	0	5
- General	7	3	0	0	0	1	0	4	1	3
- Practical	3	2	6	4	6	4	4	4	0	7
<b>Contextual and other factors</b>										
<i>Contextual factors</i>										
Family	1	3	0	1	0	2	0	1	3	0
- Responses	0	0	0	1	0	0	0	0	0	2
- Support	0	0	0	0	0	4	1	0	3	2

	T1	T2	T3	T4	T5	Pa	Pb	Pc	Pd	Pe
Social network	0	3	0	1	0	0	0	0	0	2
- Response	0	0	0	0	0	1	4	1	0	3
- Support	0	0	0	0	1	8	0	0	4	4
Services	3	0	1	0	0	2	0	3	1	1
- Approach to relationship issues	1	2	0	3	0	1	1	0	0	0
- Barriers to seeking or accessing services	6	2	0	1	0	2	0	4	1	0
- Formal therapy	8	0	0	1	0	0	0	0	0	3
- Involvement of partner in rehab	5	0	1	0	5	3	1	0	1	0
• Formal	0	0	0	0	0	0	0	0	0	0
• Informal	0	0	0	0	0	1	0	0	0	1
- Partner unmet needs	1	2	3	1	0	14	3	2	8	0
- Unmet needs (gap)	0	0	0	0	0	0	0	2	0	0
<i>Non-TBI attributions</i>										
Age	1	0	0	0	0	0	0	3	0	3
Transitions	2	13	1	0	0	5	1	1	2	3
Other non TBI	1	1	3	1	1	1	0	4	2	7

## **Appendix 16. Journal author guidelines: NeuroRehabilitation**

### **AIMS AND SCOPE**

*NeuroRehabilitation* is an international journal, which emphasizes publication of scientifically based, practical information relevant to all aspects of neurologic rehabilitation. Manuscripts cover the full life span and range of neurological disabilities including stroke, spinal cord injury, traumatic brain injury, neuromuscular disease, and other neurological disorders. Information is intended for an interdisciplinary audience.

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- Manuscripts must be in MsWord format including Tables and Figures (they need to be at the end of the manuscript and NOT separate file if possible).
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  - Abstract/Keywords
  - Introduction
  - Body of text (divided by subheadings)
  - Conclusion
  - Declaration of Interest
  - Acknowledgement
  - References
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- Abstract
- Keywords.
  - Abstract format: BACKGROUND, OBJECTIVE(S), METHODS, RESULTS AND CONCLUSION

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- Each figure should have a self-explanatory caption. The captions to all figures should be typed on a separate sheet of the manuscript.
- Photographs are only acceptable if they have good contrast and intensity.

## REFERENCES

- For citations, follow APA style.

## FOOTNOTES

- Footnotes should only be used if absolutely essential. In most cases it is possible to incorporate the information in the text.
- If used, they should be numbered in the text, indicated by superscript numbers and kept as short as possible.



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